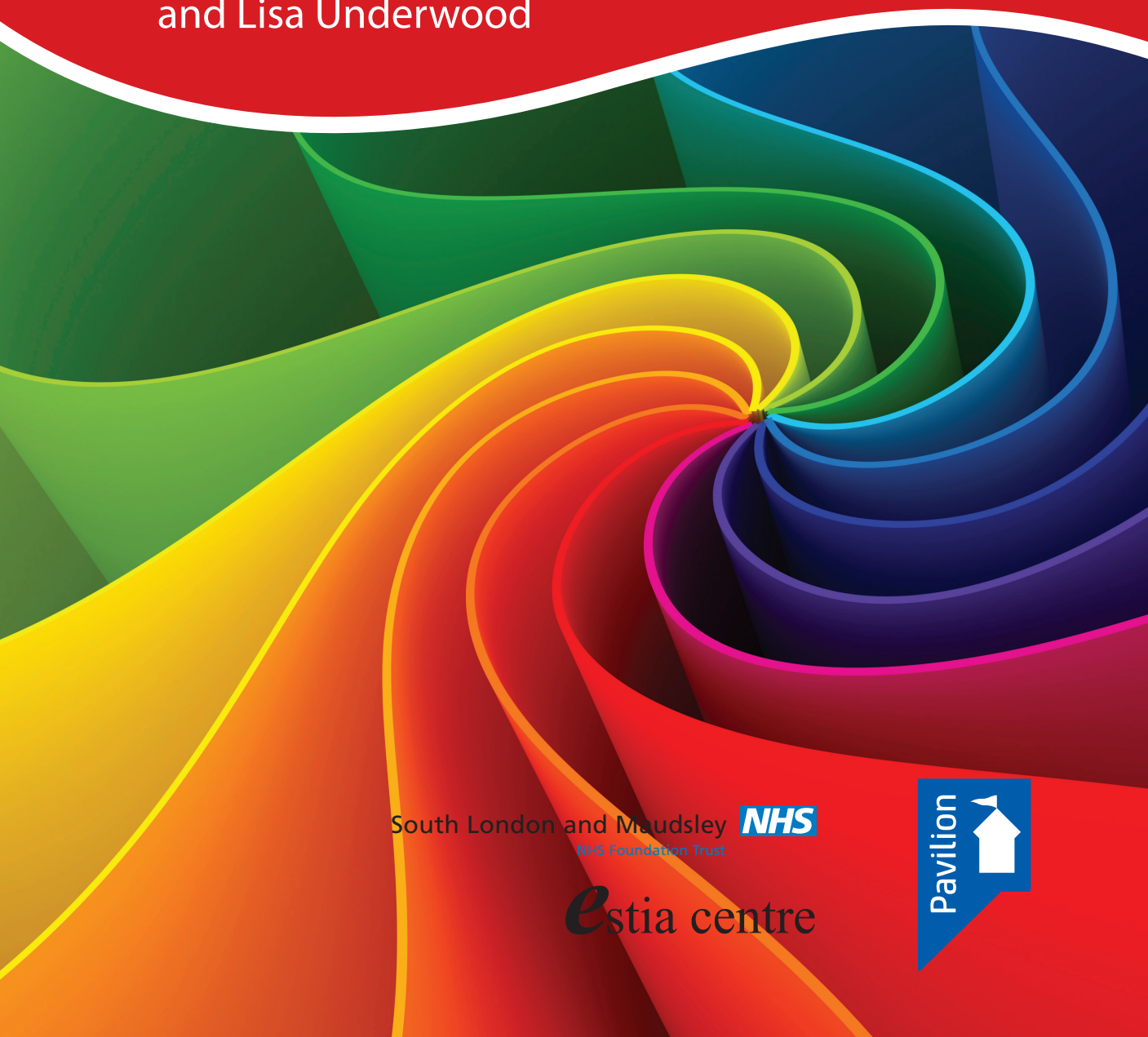
Autism Spectrum Conditions

A guide

Eddie Chaplin, Steve Hardy
and Lisa Underwood



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Published by:
Pavilion Publishing and Media Ltd
Rayford House, School Road,
Hove, BN3 5HX
Tel: 01273 434943
Fax: 01273 227308
Email: info@pavpub.com
Web: www.pavpub.com

Published 2013.

A catalogue record for this book is available from the British Library.

ISBN: 978-1-908993-58-8

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Editors: Eddie Chaplin, Steve Hardy and Lisa Underwood
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Cover design: Emma Dawe, Pavilion Publishing and Media Ltd
Page layout and typesetting: Katherine Paine, Pavilion Publishing and Media Ltd
Printing: CMP Digital Print Solutions

Dedication

We would like to dedicate this book to the memory of Yolanda Zimock, who died prematurely in 2012, aged 47.

Yolanda was a keen advocate for people with autism and intellectual disabilities. In her short life she was a member of Lewisham Speaking Up and a founding member of the Tuesday Group. As an active member of these groups, Yolanda was never afraid to speak her mind and always had an opinion, which was promoting the rights of people who had less of a voice in society. Her work promoting the mental health needs of people with intellectual disabilities and autism saw her regularly contributing to service consultations, training support workers, and presenting at national conferences. Along with other members of the Tuesday group, she published several journal articles relating to her experiences.

Finally, our greatest memory of Yolanda is as a friend with a great sense of humour, which was often dry, but always witty, and left you thinking 'Is she serious?', until you caught her having a quiet giggle to herself out of the corner of your eye.

Contents

Preface

Autism Spectrum Conditions: A guide is for staff working in social care and health services, as well as families, carers and anyone else who supports people with autism spectrum conditions (ASC), with or without additional intellectual disabilities.

The aim of the book is to provide a comprehensive introduction to working with people who have ASC. The book addresses the needs of people with ASC across the lifespan and across the range of intellectual functioning. Though the content is grounded in evidence-based practice and recent research, the text is intended to be as practical as possible, offering insight into the everyday lives of people with ASC and how staff can best support them.

Terminology and abbreviations

Contributions from professionals working in health, social services and charitable organisations have been written in person first language. There are a number of umbrella terms that describe conditions on the autism spectrum that are in everyday use. The arguments for which terminology should be used are many. Given the range of terminology that describes autism and the lack of consensus from different stakeholders, contributors use their preferred term, whether it is autism, autism spectrum conditions (ASC), autistic spectrum disorder (ASD) or any variants of these. This is also a reflection of the wide range of backgrounds that the contributors come from.

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An introduction to autism spectrum conditions

Lisa Underwood, Richard Mills, Eddie Chaplin and Steve Hardy

The National Autistic Society describes autism as:
'*… a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours*' (NAS, 2012).

Terms used to describe ASC include childhood autism, autistic disorder, high-functioning autism, Asperger syndrome, atypical autism and pervasive developmental disorder. It is common for people to be referred to as having either low- or high-functioning ASC. This can be seen as equivalent to those with and without intellectual disability, but is not a diagnostic classification (Knapp *et al*, 2009; National Audit Office, 2009a).

Background

It is over a century since the term 'autism' was first used by Paul Eugen Bleuler (Kuhn & Cahn, 2004), but it was only in the latter part of the 20th century that the condition was fully described. During this period, autism was thought of as a disorder of psychological attachment; early onset schizophrenia; a biological disorder of genetic origin, and even 'extreme maleness'. More recently it has come to be seen as a spectrum of diverse neurodevelopmental conditions. These conditions are said to form

a spectrum because although all individuals with ASC have difficulties in social communication, interaction and imagination, their functioning is affected in different ways (DH, 2010). The early association of autism with schizophrenia is described in **Chapter 2: Autistic spectrum disorders: psychopathology and co-morbidity**.

In the early 1940s, Leo Kanner (1943) and Hans Asperger (1944) made significant inroads into how we understand ASC today. Although Kanner and Asperger had never met, they sought to differentiate autism from other disorders and both argued that it was innate (genetic). The clarity of Kanner's writing allowed others to identify similar children to those reported in his study, but it was many years before autism was accepted as a distinct condition. Ideas in psychiatry during Kanner's time were strongly influenced by psychoanalysis; Kanner's observations were seized upon and ASC were portrayed as primary disorders of psychological attachment (Bettleheim, 1967), a view that lingers on in some parts of the world. Asperger's work was unknown in the UK until the 1980s (Wing, 1981), but ahead of his time in many ways, Asperger advocated research into the biological nature of ASC. Asperger also described positive aspects of his young patients, noting their success in science and the arts.

During the 1960s in the UK, the frustration of parents of children with ASC at the lack of recognition and support led to a movement that was to galvanise interest in ASC. Those parents were convinced that ASC were different from other disorders and, although they dismissed psychodynamic explanations, it was only through empirical research that such ideas were debunked and ASC were defined as neurobiological conditions (Rimland, 1964; Schopler, 1965; Folstein & Rutter, 1977).

Wing and Gould (1979) described three sub-groups of autism in children: aloof, passive, and active but odd, defining how they differed within the triad of impairments of social impairment, verbal and non-verbal language impairment, and repetitive/stereotyped activities.

The three sub-groups described are:

1. **The aloof group:** individuals are often indifferent to others and do not initiate or react to social overtures.
2. **The passive group:** individuals may respond to social overtures but are unlikely to initiate them themselves. They may be passive recipients of social overtures and get some pleasure from this on occasion.

3. **The active but odd group:** this group is egocentric in terms of its interactions, which are one-way. Their approach to others can be both inappropriate and odd in manner, with no desire to reciprocate others' interests and inattention to the social overtures of others.

Wing added a fourth category in 1996.

4. **The stilted group**: individuals are usually high functioning and can initiate and maintain social overtures, albeit at times characterised by excessive formality.

The recognition of autism spectrum conditions

Signs of ASC may be observed in children as young as 12 months. However, a formal diagnosis is not usually made until at least three years of age (Filipeck *et al*, 1999; Ozonoff *et al*, 2010; Medical Research Council, 2001). The average age of diagnosis is around six years old for autism (Andrews *et al*, 2009) and around 11 years old for Asperger syndrome (Howlin & Asgharian, 1999; Levy *et al*, 2009).

Since ASC are a relatively new concept, it is common for older individuals to remain undiagnosed in adulthood (Brugha *et al*, 2011; National Audit Office, 2009b). It is recommended that diagnoses should always be carried out by multidisciplinary professionals with specific expertise in the assessment of ASC (NICE, 2012). However, there is a lack of clinicians with this specialist training (National Audit Office, 2009a). Therefore, few individuals receive comprehensive diagnostic assessment and the identification rate of ASC in the general population is estimated to be as low as 1–4% (National Audit Office, 2009b).

There is debate on the stability of ASC symptoms over time (Matson *et al*, 2008; Seltzer *et al*, 2003). It is thought that most individuals who receive a diagnosis in childhood will meet the criteria for ASC as adults (Billstedt *et al*, 2005). However, studies have reported improvements in functioning and behaviours, particularly among people with high-functioning ASC (Esbensen *et al*, 2010; Marriage *et al*, 2009; Piven *et al*, 1996). The strongest predictors of adult symptoms of ASC appear to be childhood IQ and speech before five years of age (Billstedt *et al*, 2007). If services are to be needs rather than diagnosis driven, it may be useful to reassess symptoms across the lifespan particularly for those diagnosed early in childhood (Bennett *et al*, 2005).

Epidemiology: causes, patterns and effects

A single cause for ASC has not been identified, but there appears to be a number of genetic components (Sokol & Lahiri, 2011). Some chromosomal conditions are associated with autistic behaviours although not all individuals with these disorders will meet the criteria for a diagnosis of ASC (Piven *et al*, 1997). These include phenylketonuria, tuberous sclerosis, Fragile X syndrome and Turner's syndrome (Medical Research Council, 2001).

Writing in the *Lancet*, Spence and Thurm (2010) stated that:

'We still do not know what autism is or to be more precise what "the autisms" are. The heterogeneity of this disorder both behaviourally and aetiologically, works against even the most well designed trials. There remains a long list of issues that are difficult to even measure and certainly to account for in any sample of individuals with autism. These factors include the environmental context, other treatments, co-morbid conditions, and as yet unknown differences in genetics and neuropathophysiology. Ultimately the challenge is to define subtypes within this disorder.'

Despite this lack of clarity, much progress has been made in recent years in our understanding of people with ASC, the difficulties they face, and the best ways they can be supported. Controversies remain; there is great debate about whether we are experiencing an 'autism epidemic' (Charman, 2011). Although it does appear that rates of ASC are increasing over time (the estimate in 1978 was just 0.04%) the reasons for this are complex (Baron-Cohen *et al*, 2009). Most older studies measured the prevalence of autism rather than the wider spectrum of conditions that are included in more recent estimates. In addition, regardless of whether or not the actual rate of ASC has increased, the number of individuals identified and receiving a diagnosis has increased. This is largely because of improvements in awareness and recognition, greater provision of services and wider diagnostic criteria (Barbaresi *et al*, 2008; Medical Research Council, 2001).

Currently, the most commonly quoted prevalence of ASC among the general population is one per cent. However, estimates actually range from 0.04 to 1.57% (Baron-Cohen *et al*, 2009). The exact number of people with ASC in the UK is currently unknown (Department of Health, 2006; National Audit Office, 2009b).

The majority of early research on ASC focused on children but there is increasing interest in adults, not least to confirm or refute whether ASC are becoming more common. If theories of an increasing rate of ASC are correct, there should be much lower rates among older adults (Brugha *et al*, 2011). However, the few studies that have been carried out on adults found similar rates of ASC as those studies on children (Baron-Cohen *et al*, 2009; Brugha *et al*, 2009; Brugha *et al*, 2011).

There is consistent evidence that ASC are more prevalent among males than females with the ratio varying between 2.5:1 and 4.5:1 (Barbaresi *et al*, 2008; Carter *et al*, 2007; Centers for Disease Control & Prevention, 2009). The evidence for differing rates according to ethnicity is somewhat mixed. Some studies have found higher rates among white individuals and an under-representation of people from black and ethnic minorities within ASC samples (Centers for Disease Control & Prevention, 2009; Mandell *et al*, 2008). However, it is likely that selection or referral biases and under-diagnosis partially account for these differences (Begeer *et al*, 2008).

There is evidence that life outcomes for individuals with ASC are generally poor, while burden on carers is often high (Hare *et al*, 2004; Howlin *et al*, 2004). Research on outcomes for people with ASC began in the late 1960s when those children who were among the first to be diagnosed reached adulthood. Studies were mainly descriptive but found indications that adult outcome, in terms of social functioning, for most of those with ASC was poor and appeared to be related to IQ and verbal skills (Lockyer & Rutter, 1969; Lotter, 1974; Rutter *et al*, 1967). Kanner (1971) explored the 'destinies' of the original sample that defined the clinical criteria for autism and surmised that those who were not admitted to hospital and lived in a supportive environment had a better outcome. Lotter (1974) commented that '*...it remains easier to predict a poor outcome than a good outcome*' (pp. 273). Research that followed largely confirmed these earlier findings. Although, in general, outcomes for people with ASC appear to be improving over time as their problems are recognised earlier and they now have more opportunities than in the past (Howlin, 1997; Howlin & Goode, 1998).

It appears that individuals with ASC are at higher risk of additional mental health problems; although most studies have been on children and adolescents (Bradley & Bolton, 2006; Matson *et al*, 2010). There is evidence that challenging behaviour is also highly prevalent among individuals with ASC (Holden & Gitlesen, 2006). Aside from the repetitive and restricted

behaviours that are characteristic of people with ASC, specific problems associated with ASC include aggression, self-injurious behaviour and hyperactivity (Levy *et al*, 2009; Tsiouris *et al*, 2003).

Concern in the UK about service provision for people with ASC has been highlighted by the Department of Health (2006; 2009) and the National Audit Office (2009a,b). Reports from these bodies conclude that current knowledge is lacking with regards to the number of people with ASC using services, the needs of people with ASC and the effectiveness of service provision. In the UK, significant changes in policy and legislation have taken place in recent years with the passing of the Autism Act (2009) and subsequent implementation of the Autism Strategy (Department of Health, 2010). Clinical guidelines on the recognition, referral, diagnosis and management of ASD in children and in adults have been published by the National Institute of Health and Clinical Excellence (NICE, 2012).

Conclusion

Our understanding of ASC has progressed from the realms of armchair theory to respected science and we have gained a better understanding of ASC through systematic study. Through scientific studies we now know that ASC results from differences in the structures and neurological processes in the brain and is not a result of dysfunctional parenting. We now know there to be many causes. We use the term to describe a constellation of psychological states with broadly similar features rather than a specific syndrome.

We now know that ASC are present from birth or very early life and develop gradually, not through a single event. Developmental trajectories and outcomes differ from person to person, but we do not yet know why. There are many more boys than girls with ASC, but recent research suggests this difference may be less than was initially thought.

From studying autism symptoms we observe that ASC affect natural social development and communication – where even subtle differences can have devastating effects on social relationships and learning. We know that problematic behaviours are not a result of internal pathology, but arise from stress and anxiety and an inability to communicate. It is also apparent that the core features of ASC are usually accompanied by other psychological, neurological and sensory disorders. This knowledge is important for intervention and outcome.

From studying cognition and intelligence we have become aware of a particular style of thinking and learning in ASC and understanding this enables us to be more effective in communication, reduce difficulties and develop strengths.

ASC have benefitted from the explosion in genetics research, but we have yet to feel the full impact. Traits of ASC are often found in families, but ASC are not wholly explained by genetic factors. There is no 'gene for autism'. Epidemiological studies and classification of ASC confirm these are no longer the rare conditions they were once held to be. Despite a rapid increase in the number of ASC treatments the evidence base for interventions is weak and there are too few high quality studies. There is no single treatment for autism. ASC are neurodevelopmental conditions that have no known prevention or cure.

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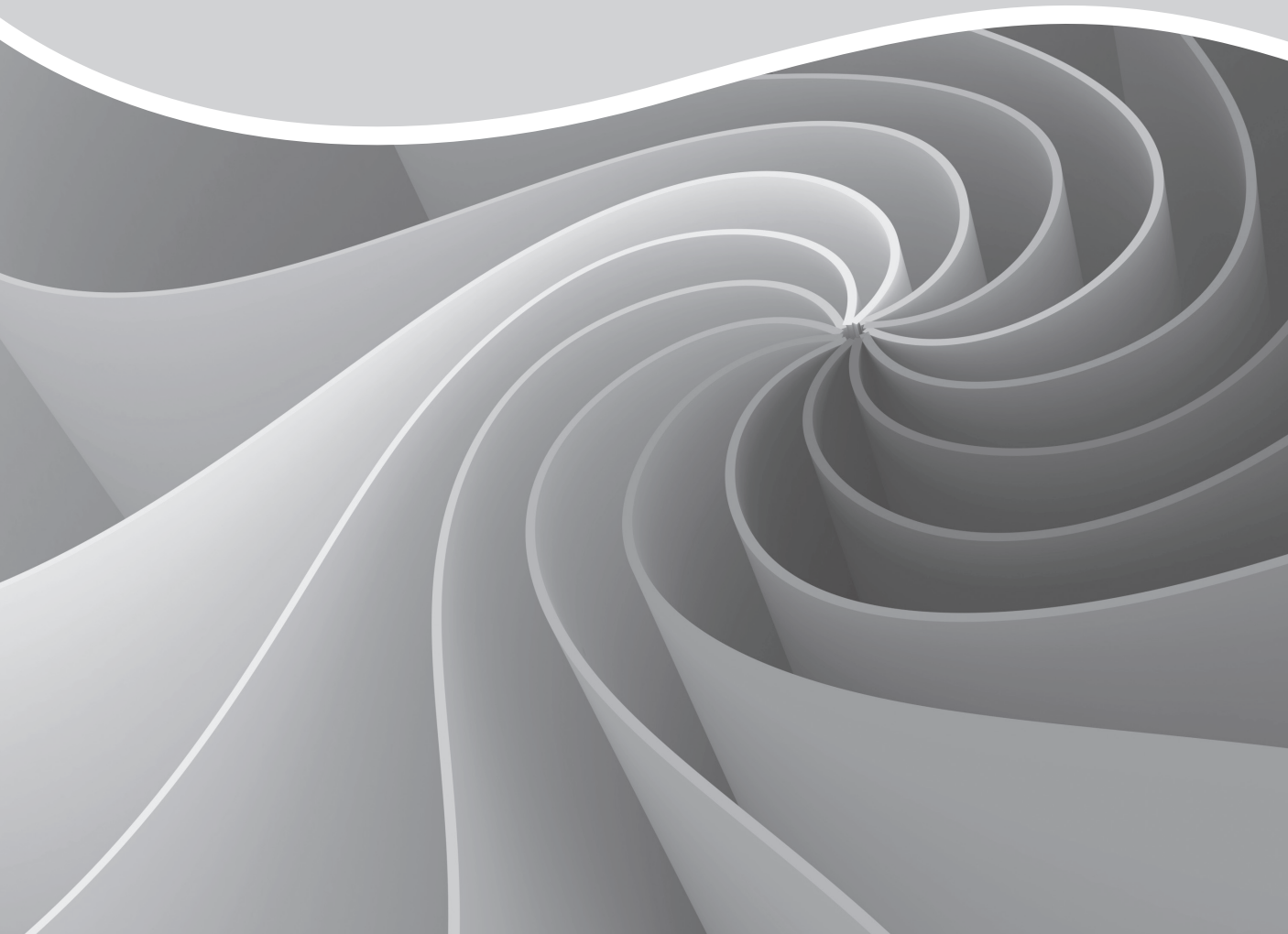
Part 1:

Clinical aspects relating to the assessment and treatment of autism spectrum conditions and co-morbid mental health problems



Chapter 1:

The assessment and diagnosis of autism spectrum disorders

Debbie Spain and Dene Robertson

Introduction

Autism spectrum disorders (ASD) are lifelong conditions characterised by qualitative impairments in reciprocal social interaction, communication, and restricted and repetitive interests and behaviours (WHO, 1992), which occur in up to one per cent of the population (Baird *et al*, 2006; Brugha, 2009). There is a wide spectrum of symptom severity, ranging from subtle socio-communication deficits to severe symptoms that are highly disabling. Although ASD begin in childhood, people may be referred for diagnostic assessment during either childhood or adulthood. The purpose of this chapter is to:

- review the key features of ASD and how they relate to specific diagnoses
- address some practical issues that may assist in the assessment of a person with a possible ASD
- provide a brief guide to some of the tools that can be used to support a diagnostic assessment
- highlight the importance of a search for clinical features of co-morbid mental health conditions
- emphasise that an adequate assessment should include consideration of a person's wider physical, social and psychological needs.

Key features of autism spectrum disorders

The 10th edition of the International Classification of Diseases (ICD-10), published by the World Health Organization, is the diagnostic manual for physical and mental health problems in Western Europe. **Table 1.1** summarises the ICD-10 diagnostic criteria for childhood autism (item F84.0).

Table 1.1: Summary of the International Classification of Diseases 10th edition (ICD-10) diagnostic criteria for childhood autism (item F84.0)

Domain	ICD-10 diagnostic criteria	Symptoms and signs
Early abnormalities in development (required for a diagnosis of childhood autism only)	*Abnormal or impaired development before the age of three years in >1 of:* 1. Receptive or expressive language as used in social communication 2. The development of selective social attachments or reciprocal social interaction 3. Functional or symbolic play	Clear delay in use of speech to communicate No single words by age two years No phrase speech by three years
Social	*Qualitative abnormalities in >2 of:* 1. Failure to adequately use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction 2. Failure to develop peer relationships that involve a mutual sharing of interests, activities, and emotions	Lack of direct eye contact and poor modulation of eye contact to regulate social interactions Restricted or inappropriate range of facial expression Lack of emotional expression Absence of close sharing friendships or relationships

Table 1.1: Summary of the International Classification of Diseases 10th edition (ICD-10) diagnostic criteria for childhood autism (item F84.0) (continued)

Domain	ICD-10 diagnostic criteria	Symptoms and signs
Social (continued)	3. Lack of socio-emotional reciprocity or lack of modulation of behaviour according to social context or a weak integration of social, emotional and communicative behaviours 4. Lack of spontaneous seeking to share enjoyment, interests or achievements with other people	Dislike of physical contact and impaired ability to comfort others Lack of social chit-chat or 'small talk' when in company Abnormal play – dislike of shared play, lack of symbolic use of toys in childhood
Communication	*Qualitative abnormalities >1 of:* 1. Delay or total lack of spoken language, not accompanied by an attempt to compensate through the use of gesture or mime (childhood autism only) 2. Relative failure to initiate or sustain conversational interchange with reciprocal responsiveness 3. Stereotyped and repetitive use of language or idiosyncratic use of words or phrases 4. Lack of varied spontaneous make-believe or social imitative play	Poor flexibility in language expression Lack of descriptive, conventional, or informative gestures Lack of creativity and fantasy in thought processes Lack of emotional response to another's verbal and nonverbal overtures Impaired use of cadence of speech to reflect communicative intent Use of echolalia, neologisms, stereotyped speech, and pronoun reversal Lack of spontaneous conversation or sharing of personal information

Table 1.1: Summary of the International Classification of Diseases 10th edition (ICD-10) diagnostic criteria for childhood autism (item F84.0) (continued)

Domain	ICD-10 diagnostic criteria	Symptoms and signs
Behaviour	*Restricted, repetitive, and stereotyped patterns of behaviour, interests and activities in >1 of:* 1. An encompassing preoccupation with >1 stereotyped and restricted interest which is abnormal in content or focus or >1 interest which is abnormal in intensity and circumscribed nature 2. Apparently compulsive adherence to specific non-functional routines or rituals 3. Stereotyped and repetitive motor mannerisms such as hand/finger flapping or twisting or complex whole body movements 4. Preoccupations with part-objects or non-functional elements of play materials	Imposition of non-functional rigidity and routine on everyday and novel experiences Resistance to change in routine or environment Abnormal play-preoccupation with parts of objects Lack of spontaneity, initiative and creativity Lack of spontaneous imitation/mirroring of others Unusual sensory seeking or avoidance behaviours Increased sensitivity to noise Temper/outbursts Aggression Self-injury Anxiety symptoms Difficulties in the educational or occupational environment Sleep difficulties Eating disturbances

In addition to childhood autism, the ICD-10 contains a number of other diagnoses that are included under the umbrella term ASD (known in ICD-10 as 'pervasive developmental disorders'). In the main, ASD are 'partial phenotype' diagnoses in which the individual meets fewer diagnostic criteria than a person with childhood autism (phenotype describes observable traits that result from interactions between a person's genes and the environment eg. behaviour). **Table 1.2: Features of childhood autism and high functioning autism** illustrates the relationship between the symptoms found in childhood autism and 'high functioning' autism (this term does not occur in ICD-10 but is in common use).

Table 1.2: Features of childhood autism and high functioning autism

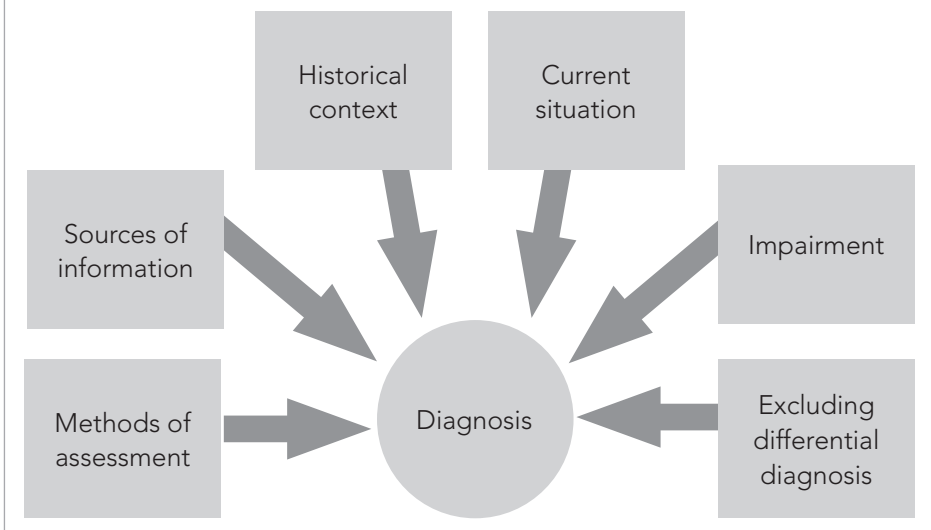
Childhood autism	High functioning autism
Intellectual disability	Language delay
Language delay	Ritualistic behaviour
Ritualistic behaviour	Social interaction
Social interaction	Communication
Communication	

The ICD-10 also includes a number of other diagnoses that are used when a limited number of symptoms is present, or where there is an absence of information about the person's early childhood development. These include atypical autism and pervasive developmental disorder – not otherwise specified.

ASD diagnostic assessment: an overview

Figure 1.1: Diagnostic assessment of autistic spectrum disorders: an overview illustrates the essential components of a complete assessment for ASD. Ideally, such an assessment of ASD should be undertaken by a multidisciplinary team and information should be gathered from a variety of sources.

Figure 1.1: Diagnostic assessment of autistic spectrum disorders: an overview



Practical considerations

In order to ensure that all relevant historical information is obtained, it is important to make concerted efforts to engage individuals and their families or carers in the assessment process. Such considerations may start early in the assessment process; for example, many people with ASD are uncomfortable using the phone, and may prefer to make an appointment by letter. People with suspected ASD may prefer that the appointment is arranged via a family member or carer, and this is appropriate where consent is clearly given. Given that a diagnostic assessment of ASD can be lengthy, it is important to check whether individuals would prefer the assessment to take place over one or several appointments.

People with ASD often find it difficult to tolerate uncertainty and ambiguity, so it is important to offer clarity about the structure and focus of the assessment from the outset. This may include providing an advance summary of what the assessment is likely to involve, its duration, and possible outcomes. When initially meeting individuals for a diagnostic assessment, it is appropriate to reiterate the aims and focus of the meeting, and identify whether the person has any particular expectations or issues for discussion.

People with ASD may be sensitive to noise, light, or extraneous stimuli. A failure to accommodate these needs may mean that individuals find it difficult to concentrate during a clinical interview or become distressed. Thus, the clinician should offer flexibility of environment. As is good clinical practice, it is advisable to inform individuals whether any interruptions to the assessment are anticipated; for example, phone calls or scheduled break times, in order to reduce unpredictability or distraction.

Clinicians undertaking a diagnostic assessment should be mindful of the language and terminology they use. People with ASD and/or intellectual disability may find it difficult to understand complex language, abstract terms, or metaphors. Use of medical jargon and colloquialisms should therefore be kept to a minimum. It is often helpful to confirm understanding by asking the person to explain to you in their own words what you have told them. People with ASD may experience great difficulty in 'turn-taking' in conversation. Therefore, using a combination of closed and open questions may elicit a fuller range of responses.

The diagnostic assessment

Screening tools

Screening tools include the Autism Quotient (AQ) (Baron-Cohen *et al*, 2001) and the Social Responsiveness Questionnaire (SRS) (Charman, 2007). These are self-report or carer-completed forms containing a number of questions, the answers to which have been found to increase or decrease the probability that a person may have an ASD. Screening tools may be employed by professionals in primary or secondary healthcare, social services, voluntary organisations, or by the person concerned. The diagnosis of an ASD should not be included or excluded on the basis of the results of screening tools.

Referral for a specialist diagnostic opinion

This may take many forms. However, at its simplest, a standard psychiatric history and mental state examination may be adapted to explore potential features of an ASD. In clear-cut cases this may be enough to establish the presence or absence of an ASD in either a young person or adult. Where there is an absence of clarity, or in more complex clinical presentations, diagnostic assessment tools may be used.

The Autism Diagnostic Interview – Revised (ADI-R) (Lord *et al*, 1994)

This is a standardised, semi-structured interview conducted with a parent or caregiver. The interview assists the clinician to perform a detailed survey of language development, social interests, play and social interaction, communication and other patterns of behaviour. Cut-off scores allow for diagnosis. Other means of obtaining a semi-standardised developmental history are also available.

The Autism Diagnostic Observation Schedule (ADOS-G) (Lord *et al*, 2000)

This is a semi-structured, standardised assessment of communication, social interaction and use of materials. There are four different modules which are used depending on age and language skills. Modules toddler, 1 and 2 tend to be administered to individuals who have little or no speech; modules 3 and 4 are typically used for adolescents and adults, specifically those individuals who have good use of speech. Cut-off scores allow for diagnosis (Lord *et al*, 2000).

Administration of both the ADI-R and ADOS requires completion of training and attainment of inter-rater reliability.

Ruling out other diagnoses (differential diagnosis)

While a characteristic early childhood development and mental state presentation during adulthood might strongly support a diagnosis of ASD, things are not always so straightforward. For example, when the individual is an adult, a developmental history might not be available, and current features might be explained in terms of one or more other diagnoses. Establishing the diagnosis of an ASD in such a case is likely to require specialist expertise – usually within secondary or tertiary mental health services.

Assessment for possible co-morbidity

As reviewed in **Chapter 2: Autistic spectrum disorders: psychopathology and co-morbidity**, ASD are associated with higher than general population base rates of other neurodevelopmental disorders, including epilepsy, intellectual disability, attention deficit hyperactivity

disorder (ADHD) and tic disorders. An ideal assessment is not complete until these have been actively explored. This may not be complex; for example, in one case it may be obvious that a person does not have a intellectual disability, but in another neuropsychological testing of adaptive behaviour may be required. Depressive disorders and anxiety disorders are very common in people with ASD. People with ASD are often extremely poor at explaining their own and others' mood states (ie. they have a relative alexithymia) so evidence of depression and anxiety disorders should always be actively sought. Sometimes – rather than relying on a person with an ASD to spontaneously report mood symptoms and describe their own mood state – it is necessary to examine changes in behaviour and infer mood or other mental state abnormalities on this basis. There are a number of other pitfalls for the clinician who is assessing a person with ASD for co-morbid mental health difficulties. For example, symptoms associated with co-morbid illness should not be confused with the ASD itself. For example, it is important to differentiate ritualistic behaviour that is distressing, resisted and due to obsessive compulsive disorder from the 'egosyntonic' un-resisted ritualistic behaviour associated with ASD. This is critical as failure to identify co-morbidity deprives people with ASD of treatments that may significantly reduce distress and improve functioning.

The assessment of wider needs

People referred for assessment should not be seen in the light of medical diagnosis alone, and a more holistic approach, in which the individual's physical, psychological and social needs are considered, should be taken. The National Institute of Health and Clinical Excellence (NICE, 2011; 2012) recommends that in addition to diagnostic assessment there should be assessment of co-morbidity (see the previous section), adaptive functioning and risk. The assessment of wider social and psychological needs may be improved by the use of varied means of acquiring information. These include third party reports, self, informant or clinician-rated questionnaires, behavioural observation, and/or functional analysis of behaviour. The assessment methods employed are likely to depend on the person's intellectual ability, level of language and comprehension, and whether others (including parents, carers or teachers) are able to take part in the assessment process. The assessment and management of risk to both self and others is an integral part of the care of any individual. Such risks may include physical, sexual and financial vulnerability, self-harm, self-neglect, challenging behaviour, illegal activity, and the possibility of harm

to others. On the other hand – as with any other population – there may be minimal risk, though this should always be established actively rather than assumed. When considering risks to self and others, there is often a complex relationship between the symptoms of ASD itself, symptoms of co-morbid mental health conditions, and the wider circumstances.

After the diagnostic assessment

It is important to note that reactions to receiving a diagnosis of ASD may be positive, negative or mixed (NICE, 2012). People may feel relieved to finally have an explanation for their difficulties; on the other hand, they may feel confused, worried or distressed by what this means. Individuals should be given clear, accurate information regarding their condition – using methods of communication that are most meaningful to the individual – and afforded the opportunity to ask questions of the assessing team. It may be helpful to convene a family meeting, even where the person concerned is an adult. People newly diagnosed with ASD may worry that a diagnosis will impact on their educational or employment opportunities, or that they may incur stigma and discrimination. Clear signposting to sources of support as well as relevant legislation should be provided. It should always be remembered that carers may themselves have unmet needs and have a statutory right to an assessment under the Carers (Recognition and Services) Act (1995).

Diagnostic examples

John

John is a 20-year-old unemployed male, living with his parents. His parents requested an assessment due to concerns that John is very socially isolated and does not have age-appropriate independence skills. He spends almost all of his time at home either researching military history or playing role-playing games on the internet. He has previously attended several college courses, but was unable to continue past the first term. His parents think this was because he could not manage the informal structure of lessons and self-directed learning. He also had difficulty with making friends, and was teased by classmates. As John's parents get older they are increasingly worried about how he will support himself in the future.

Developmental history

With John's consent, his parents provided an account of his developmental history. There was some delay in language acquisition; John started using simple phrased speech aged four. He has a history of using repetitive phrases and echolalic speech (repeating back what people have said). John attended mainstream schooling between the ages of five and 16. Consistent difficulties were observed by his teachers; in particular John was quiet and reserved, and rarely approached others, even if he needed help or had hurt himself. He declined to engage in group activities, and spent break times alone. He had two friends during secondary school who were described as very quiet and shy; they did not socialise outside of school. John did not seem very imaginative as a child: he did not play pretend games, and although he had lots of toys, he would only line these up or take them apart.

There was a history of communication difficulties. John has never engaged in 'small talk'. He seldom initiates a conversation, and talks exclusively about his own interests. His parents reported that John has never seemed very expressive; it is impossible to tell how he is feeling and he cannot easily describe his emotions. He has a longstanding interest in military history, and a vast collection of books, newspaper articles and DVDs. His knowledge of facts relating to World War I is exceptional. He has been known to write to the BBC and publishing companies if minor details are misquoted. It was reported that John has never liked changes to his routine – he would become distressed if his mother took a different route to school, and has a restricted repertoire of foods that he will eat. He has always tended to undertake activities – for example, eating and washing – in his 'own way', and can become very upset if he is unable to do this.

Present state assessment

At assessment, John presented as shy and hesitant. His eye contact was reduced and there was poor modulation of facial expressions. His use of gestures was limited. His speech was normal in rate, but monotonous in tone. His speech had a pedantic and precise quality, and he tended to repeat phrases. He rarely initiated comments, and needed prompting to provide detailed answers to questions. He agreed that he has a limited social network, although reported that he is happy to spend time alone engaged in his interests.

Diagnosis

John's history demonstrated language and social abnormalities that began prior to age three, qualitative abnormalities in social interaction, qualitative abnormalities in communication, and a restricted repertoire of interests and activities. As there were no other more likely causes for his difficulties, a diagnosis of childhood autism was made.

Jane

Jane is a 43-year-old female, living alone. She works part-time as a librarian. She has a limited social network, and has never had an intimate relationship. She finds it hard to know how to talk to people both at work and in everyday situations. She requested an assessment because she would like to better understand why she finds social situations difficult. She has scored positively on a number of screening questionnaires for ASD that she discovered on the internet.

Developmental history

Jane's parents are deceased, and she had no aunts or uncles who might have been able to provide a collateral developmental history. She was not aware of any delay in attainment of developmental milestones. She described herself as clumsy and has never been able to catch a ball, swim or ride a bike. She attended mainstream school, where she attained reasonable exam results. She was bullied by her classmates, although she was not sure why. She was never invited to parties, and she continues to ruminate about this. She said that she has difficulty with making conversation, particularly with unfamiliar others. She finds it easier to talk about the same few topics, which people have said is frustrating and irritating. She cannot easily 'chat for the sake of chatting', and doesn't know how to reply when people make 'small talk'. She recalls having played with dolls as a child – specifically pushing them around in a pushchair – and she enjoyed drawing.

Present state assessment

At assessment Jane used some direct eye contact, although this had a relatively fixed quality. Her facial expression was fairly flat, even when talking about her current difficulties and her past history of being bullied. Her speech was quiet and her answers were overly detailed. She tended to repeat herself and it proved difficult to interrupt her flow. She reported that she was 'sad' that she did not have friends, but had difficulty describing her feelings any further.

Assessment of wider needs

There is no significant medical history. Jane has a history of engaging in repetitive behaviours, which started in her early teens. She said that it takes her three hours to have a bath because she likes to follow a set routine – she has never resisted the urge to do this, and does not think that it is unreasonable in any way. However, about two years ago she started worrying that she might be burgled in the middle of the night if

she did not lock the front door and close the windows, and that she might blow herself up if she did not turn off the cooker. As a result, she now spends several hours a day checking that she has closed the windows and locked the front door, and turned off the gas. She finds this distressing because she would rather be spending her time more productively; however, whenever she tries to resist her urges her anxiety increases, only to decrease when she starts checking again.

Diagnosis

A diagnosis of Asperger syndrome with co-morbid obsessive-compulsive disorder (OCD) was made. This was based on the history Jane provided. It is clear that she has experienced longstanding qualitative impairments in communication and social interaction, as well as maintaining a restricted range of interests, all of which have persisted to the present day. Due to lack of corroborative information from a parent, it is not possible to establish whether age of onset of these impairments was before the age of three, but there is no reported history of speech or developmental delay. Jane describes engaging in different types of repetitive behaviours: egosyntonic repetitive behaviours that date back to her early childhood, and egodystonic routines and rituals, which started during her teens and are associated with obsessional thoughts and worries, and anxiety. In the absence of developmental delay, a diagnosis of Asperger syndrome is made, along with a diagnosis of co-morbid OCD.

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Chapter 2:

Autistic spectrum disorders: psychopathology and co-morbidity

Colin Hemmings

Introduction

This chapter will consider psychopathology and co-morbidity among people with autistic spectrum disorders (ASD). Psychopathology is the study of mental illness and abnormal or challenging behaviours and the term includes the description of symptoms. Co-morbidity describes the other conditions an individual might have in addition to the primary condition. It is important to note that sometimes conditions co-occur by chance while at other times one condition may predispose another to developing. ASD can occur together with a variety of general medical, genetic and neurodevelopmental conditions, mental illnesses and challenging behaviours. This chapter will focus on some of the mental health and neurodevelopmental conditions that people with ASD are at an increased risk of having compared to the general population. It will not consider the variety of co-morbid challenging behaviours associated with ASD, although a mental illness may sometimes be a main cause of these, or at least a contributory factor.

Background

ASD is known to co-occur with a variety of mental illnesses. It is now widely accepted that the overall prevalence of mental illnesses increases in people with ASD (Matson & Nebel-Schwalm, 2007; Simonoff *et al*, 2012). For example, depression and anxiety disorders, such as obsessive-compulsive disorder (OCD) and phobias, are increased in people with ASD (Hutton *et al*, 2008). People with ASD are also more likely to have a family history

of mental illness (Sullivan *et al*, 2012). Prevalence rates of co-morbidity of mental illness in ASD are not yet firmly established for a number of reasons. Mental illnesses are generally more difficult to detect and diagnose in people with ASD than in the general population, particularly when a person has intellectual disabilities as well. ASD is frequently associated with intellectual disabilities, which itself carries an increased risk of mental illnesses (LoVullo & Matson, 2009). The longstanding view that the majority of people with ASD also have intellectual disabilities has recently been questioned. This is because ASD are increasingly recognised and diagnosed in people with average and high IQs (Edelson, 2006). Diagnostic criteria for both ASD and mental illnesses have been refined over time making the findings of different studies difficult to compare. For all these reasons the reported rates of mental illness in people with ASD could be quite different from the true underlying rates.

Mental health assessment for people with ASD

As in people without ASD, a mental health assessment should be undertaken using a combination of methods. There will be a direct interview of the person with ASD if possible and/or the taking of a history of the presenting problems from key people such as carers and relatives to try to help understand the person's internal mental state. There will also often be evidence gained from direct observation of behaviours. These may be supplemented by the use of questionnaires or rating instruments, previous medical records and reports from sources such as education and social care. There may be physical examination and medical investigations and often these would be to exclude other diagnostic possibilities such as mental health changes caused by physical health problems.

There are many possible problems in the mental health assessment of a person with ASD. Detection of symptoms of mental illnesses largely depends on the person being able to articulate their experiences and thoughts and beliefs (Leyfer *et al*, 2006). It is impossible to diagnose mental illness with certainty in people with limited verbal communication. This would automatically include all people with ASD who have a level of IQ below around 45. But even with much higher IQs, people with ASD may be more limited in their verbal communication of distress. Differentiating mental illness from core and associated features of ASD is often difficult. Rating instruments used in the general population to assist diagnosis have

debatable validity when used for people with ASD (Helvershou *et al*, 2008). Sometimes, then, people may tend to put the reason for odd or unusual behaviours down to a person's ASD rather than consider whether or not they may be experiencing mental health problems (Xenitidis *et al*, 2007).

There is some evidence that mental illnesses in people with ASD can be missed or wrongly diagnosed in mainstream services (Raja & Azzoni, 2010). Experiences or behaviours for someone with ASD may be wrongly thought of as mental health problems. For example, it is often difficult to separate out true hallucinations from inner speech. People with ASD may often 'remember' previous conversations and think out loud about them. They will not recognise that this is considered socially odd. Incoherent speech may also be more difficult to judge in some people with ASD if it is difficult to follow the thread of their speech. Unusual preoccupations or odd ideas held rigidly by people with ASD may be particularly difficult to differentiate from delusions. Core or associated features of ASD often mask or mimic symptoms of mental illness. Social withdrawal, flattened and odd or 'incongruent' moods, poor non-verbal communication and reduced speech are commonly seen in ASD as well as in mental illnesses. People with ASD also have higher rates of sensory problems such as hearing and visual impairments. Sensory impairments may make people more susceptible to misinterpreting things they see and hear and feel.

Box 2.1: Potential difficulties for a person with ASD undergoing a mental health assessment summarises some of the difficulties a person with ASD may have during a mental health assessment.

Box 2.1: Potential difficulties for a person with ASD undergoing a mental health assessment

- Understanding the purpose of the assessment
- Understanding questions about their mental state
- Understanding concepts or ideas beyond the concrete or literal
- Expressing emotions verbally and non-verbally
- Communicating internal experiences or motivations
- Misinterpreting the behaviours or speech of others

The onset of mental illnesses may be less noticeable in people with ASD because they are less likely to have very obvious, clear-cut or typical symptoms. Atypical or unusual symptoms of mental illnesses in people with

ASD can be a change in frequency or intensity of challenging behaviours, a decline in a person's functioning or a deterioration of their skills rather than more obvious symptoms such as depressed mood or hallucinations.

The case study below illustrates an example of a presentation of depression with some atypical features in a person with ASD.

Case study: Autism spectrum disorder and depression

Danielle was a young woman aged 17 with an ASD who lived with her mother and was studying for her A levels. Her mother was worried about Danielle as she had stopped washing herself. She was also having nightmares and eating less than usual. She had been late with her homework on three occasions, which was out of character. She was referred to a psychiatrist who had experience of working with people with ASD.

At assessment Danielle spoke very little. She had a restricted number of interests and denied any loss of interest or pleasure in things, but this seemed longstanding. She presented a flat affect and monotonous voice, but her mother said this had not changed since early childhood. Danielle denied feeling sad or depressed. However, the history up to a few months ago suggested she had previously been quite obsessional about her personal hygiene. There did not seem to be any change in her level of social interaction; she had always been quite solitary. However, on questioning she stated that as she was a teenager she would now like to have a friend, but said she did not know how people went about 'getting a friend'. She also did not know 'what friends did together'. She felt that she was 'no good' at things and that people did not like her as she was 'different' and 'not like them'. Her mother had not heard her talk like this before.

Danielle was diagnosed with depression and prescribed antidepressants and given psychotherapy based on modified cognitive behavioural therapy. Her sleep and appetite and personal hygiene improved and she resumed doing her homework as she used to.

A tentative diagnosis of mental illness in ASD may sometimes be made on the basis of observations rather than the person's own account. For example, behaviour that might suggest auditory hallucinations could be a person with ASD shouting at people who are not present when this has never been their previous behaviour. Similarly, observed increased suspiciousness and increased social isolation could be suggestive of mental illness. Non-verbal evidence such as that based on observed behaviours by necessity becomes of greater importance in the assessment of people

with ASD who have more limited verbal abilities. A detailed history about someone's early life and development is crucial to help establish the right diagnosis. This developmental history needs to be complemented by a detailed knowledge of the person including their mood, speech and behaviours. It is important to get as many reliable accounts as possible of how the person usually is.

Box 2.2: Important questions in a mental health assessment of a person with ASD shows some questions to think about in a mental health assessment.

Box 2.2: Important questions in a mental health assessment of a person with ASD

- What can the *person* tell you about his or her thoughts and feelings and behaviours?
- Does this experience or behaviour appear to *trouble* or distress the person?
- Is there a detailed, pregnancy/birth to adulthood, *developmental* history?
- Is there a *family* history of any mental illness?
- Is this experience or behaviour new or very *different* or unusual for the person?
- What is the *usual temperament or mood* of the person?
- Have there been any *changes in their usual routines*?
- Is the person in good *physical health* and had *relevant investigations*?
- Are there any changes in their *sleep, appetite, weight and energy/ activity level*?
- Can any recent *upsets or negative events* explain any changes in the person?
- Have any changes in the person been reported by *more than one informant*?
- Have any changes in the person been reported in *more than one environment*?
- Are there any *risks*, for the person or for others?

Answers to any single one of these questions will be unlikely to be conclusive in assessment as symptoms of mental illness tend to come in clusters. Therefore, one odd experience on its own may be of less significance for a diagnosis of mental illness than if the person with an ASD

has a pattern of symptoms. Clinicians use various pieces of evidence from various sources to try and build up an overall guide to how likely it is that a person with ASD does have a co-morbid condition. Some of this evidence may be somewhat contradictory and it can often be impossible to give a definitive diagnostic opinion.

ASD and psychosis

Psychoses are among the most severe mental illnesses. In psychosis a person has lost touch with reality or has lost insight. The best known and described psychotic symptoms are *delusions* and *hallucinations*. It is often difficult to determine whether a person with ASD has true delusional beliefs. People with ASD have problems to varying degrees with *theory of mind* (see **Chapters 12** and **17**). So the beliefs of a person with ASD may sometimes appear persecutory as they lack the ability to understand another person's motivations. They also may have problems understanding non-verbal communication, leading to misinterpretations. One guide to whether or not an odd or unusual belief may be a delusion is whether or not the experiences or beliefs are distressing for the person. A person does not generally tend to fantasise about or imagine things which are frightening or upsetting, or believe things that cause them distress. This, however, can only be used as a rough guide as sometimes symptoms of mental illness are not necessarily upsetting for a person with ASD.

Some decades ago ASD were wrongly believed to be variants of early onset schizophrenia. The term autism was actually first used to describe a form of social impairment in schizophrenia. However, it has been recognised since the 1970s that ASD and schizophrenia are separate conditions. People can have one or other of the conditions, or less commonly they may have both. Often people who develop schizophrenia in adolescence or early adulthood have been found to have had problems with communication and reciprocal social interaction and to have obsessions, rituals and bizarre thinking dating from childhood and well before any psychotic symptoms such as delusions or hallucinations develop. There is some debate as to whether or not the prevalence of schizophrenia is increased in people with ASD (Skokauskas & Gallagher, 2010). It may be that people with ASD are more susceptible to developing short-lived psychotic episodes, which can be triggered by life events, which may be linked to limited ability to cope with stress effectively.

Whether or not a person presenting in adulthood with both autistic features and psychotic symptoms is diagnosed with ASD as well as mental illness can vary according to the diagnosing patterns of individual clinicians. This is in turn influenced by the extent of their own training and experience in caring for people with ASD. The only way to try and tell if psychosis has occurred co-morbidly on a background of ASD may be to get a very detailed developmental history, ideally from more than one source. Unfortunately, it is not always possible to obtain this history, especially if the person with ASD has moved around as a child or has been in care. The differentiation of the two diagnoses has often been described as like a 'quagmire' (Dvir & Frazier, 2011). However, many clinicians adopt a pragmatic approach, which is less concerned with diagnostic labelling and more focused on the actual symptoms or impairments. For example, many people with schizophrenia may benefit from psychosocial strategies such as social skills training, which is arguably more aimed at their autistic-type features, whether or not that person is formally diagnosed with co-morbid ASD.

There are other examples of symptoms that make differentiation between schizophrenia and autism difficult. It has also been recognised that catatonia is more common in ASD as well as in schizophrenia. Catatonia can include gross disturbances of movement, such as adopting a motionless posture for long periods. Alternatively, in a catatonic state the person may become constantly overactive and be in a state of constant excitement. Some other symptoms of schizophrenia have been described as 'negative' symptoms and these can include social withdrawal, reduced speech, and reduced motivation. Alternatively, these phenomena could be found as features of a person's ASD, also possibly influenced by many other factors such as institutionalisation, medication side effects, lack of stimulation and problems with information processing. Catatonia or 'negative' type symptoms may therefore be part of the presentation of schizophrenia, may be part of ASD, or be manifested in some people with ASD who also have co-morbid schizophrenia, or found in individuals who have neither diagnosis.

The following case study is an example of a person with ASD who developed a psychotic illness.

Case study: Autism spectrum disorder and psychosis

William was a young man in his late 30s with an ASD and mild intellectual disabilities, who lived with his elderly mother. He had always had a high background level of anxiety. He had a wide number of phobias and rituals such as touching the taps and the pipes and counting out lists of numbers. His mother made sure he was able to carry out his rituals and assisted him with these. She prepared his food in a specific way as he demanded, otherwise he would not eat.

When William's mother became seriously ill and was rushed into hospital to have major surgery, William's care manager organised for care workers to come into the house regularly to support him. The care workers were unwilling or unable to assist William with his rituals in the specific ways he demanded. Under this stress he became very agitated and verbally aggressive. At times, when angry with the support workers, his speech was incomprehensible. He began to complain of seeing slugs in his food and saw them climbing the walls when he was in bed. He also stopped eating apart from biscuits he kept in his bed and spent most of the night pacing the house angrily. He appeared convinced that the support workers were bringing in slugs to make him 'slimy' and to stop his mother coming home.

William was diagnosed with an acute stress-related psychosis and given the antipsychotic medication risperidone. His delusions and hallucinations gradually decreased in frequency and intensity after a few weeks. He developed some new rituals that he did not need assistance with. Later, his mother returned home and it was possible to discontinue his medication without relapse.

Other co-morbid conditions

There are many other examples of mental illnesses or neurodevelopmental conditions in which it is hard to establish with certainty that a person has them in addition to their ASD. Some of these are considered briefly here.

Tourette's syndrome

It has been estimated that people with ASD are more than six times more likely to have co-morbid Tourette's syndrome (Baron-Cohen *et al*, 1999). In this condition tics must have been present for at least one year for a diagnosis to be made. Examples of vocal tics are barking, belching and throat clearing. Examples of motor tics can include eye blinking and body jerking. A tic is a sudden, rapid, recurrent non-rhythmic vocalisation or motor movement which tends to be involuntary and distressing to the person. Repetitive and stereotyped vocalisations or movements in ASD may appear to be intentional and less involuntary and are often enjoyed by the person, but can be very hard to differentiate from tics.

Attention deficit hyperactivity disorder (ADHD)

People with ASD often show inattention, hyperactivity and impulsivity. Diagnosing both ADHD and ASD concurrently in a person is controversial, but is often done (Simonoff *et al*, 2012). Guidance from the National Autistic Society suggests that a diagnosis of ADHD should not be considered as an additional diagnosis unless the person's needs relating to autism have been addressed first. Someone with ADHD alone is likely to develop his or her social and interpersonal skills over time as symptoms become less severe.

Obsessive compulsive disorder (OCD)

In OCD a person typically resists (at least initially) the compulsive acts associated with obsessional ideas, impulses or thoughts. Typically, the associated compulsion is not pleasurable to the person with OCD in the way that it can be for the acts or rituals associated with the obsessions of a person with ASD. The distinction is often not clear cut or easy to discern in people with ASD. Hence many people with ASD receive the additional diagnosis of OCD.

Interventions

Once diagnosed, the treatment of co-morbid conditions in people with ASD broadly follows that in the general population. There is a consensus that medication for mental illnesses often needs to be instigated and increased even more cautiously in people with ASD. They are more likely to have general physical health problems and they tend to be more sensitive to

medication. Distinguishing medication side effects is more difficult in people with ASD as they are less likely to communicate distress. The usual range of psychosocial strategies is used for mental illnesses in people with ASD. As with medication, there is still as yet relatively little research published regarding the specific use of psychosocial interventions for mental illnesses in people with ASD.

Conclusion

ASD is associated with a large number of co-morbid conditions. There is not one simple explanation as to why such a large number of co-morbid conditions are found. It is likely to be due to a complex relationship of genetic, biological and environmental factors that themselves have either contributed to the ASD or are the result of it. An exhaustive list of all potentially associated co-morbid conditions would need to be constantly refined as new evidence emerges. The full range of mental illnesses can occur in people with ASD and overall they are more common in people with ASD than in the general population. Many symptoms of mental illness are similar to core or associated features of ASD. Additional co-morbid diagnoses are therefore not always made. In part this still depends on clinicians' own opinions as to whether the diagnosis of an additional mental illness would be clinically useful. In addition, the frequent presence of intellectual disabilities complicates assessment as does the reduced ability of people with ASD to describe their own mental states.

Mental illnesses are more difficult to detect in people with ASD and often the symptoms are more subtle or less typical than those in the general population. The relationship between ASD and mental illness is thus a complicated one. Recently there has been much more research into mental illnesses in people with ASD. For example, there have been developments in specific instruments designed to aid with the screening for, and assessment of, mental illness in people with ASD (Helverschou *et al*, 2009; Thorson & Matson, 2012). Knowledge is now steadily increasing from this research. Hopefully this evidence will continue to improve clinical practice so that mental illnesses are not over-diagnosed, nor do they go undetected and untreated in people with ASD.

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Chapter 3:

The use of medication and psychological treatments in autism spectrum conditions

Nick Britchford and Nadja Alim

Introduction

This chapter reviews the use of prescribed medication in the treatment of mental health problems in people with autistic spectrum conditions (ASC) and outlines a range of psychological interventions.

Medication

People with ASC experience a wide range of mental health problems and medication is frequently used alongside other interventions to alleviate the effect of these on individuals.

It is useful to split pharmacological intentions into two main categories:

- medication used to treat the direct impairments associated with ASC
- medication used to treat common co-morbid conditions.

There remains limited evidence for the treatment of mental health problems in relation to people with ASC. This chapter provides evidence where possible and aims to highlight the difference between evidence-based practice and extrapolated evidence drawn from people without ASC.

It is worth mentioning that in the UK there are no drugs which have received licences specifically for treating people with ASC. In the USA there

are only two drugs which have received Food and Drug Administration (FDA) approval: risperidone and aripiprazole are approved for the treatment of behavioural problems in children.

The introduction stated that people with ASC have core deficits in three main domains of functioning:

- social functioning
- communication
- imagination including flexibility of thinking and adapting to change.

Many people with autism have a co-morbid intellectual disability which leads to additional problems with intellectual, social and moral development, as well as multiple deficits in adapting their behaviour to day-to-day situations. These are frequently manifested in a range of everyday problems, which cause anxiety, distress and frustration.

Psychosocial interventions are the predominant treatment approaches, but these are increasingly combined with medication aimed at either the core features or the behavioural challenges as a consequence of these (Broadstock *et al*, 2007).

The most common co-morbid psychiatric conditions are depression, anxiety, ADHD, and intellectual disability, which may find their expression through challenging behaviour in individuals with more severe levels of intellectual impairment.

Treatment goals

Many children and adults with ASC have a range of behaviours which are a challenge to those who support them. This includes aggression, violence towards others and aggression towards themselves. Those with co-morbid intellectual disability are at even greater risk of having challenging behaviours (Matson *et al*, 2011).

The goal of treatment is to reduce the frequency, severity or impact of these behaviours. It is also frequently aimed at improving the function and quality of life of people with ASC.

Pharmacological interventions should never be seen as sole treatments, but as adjunctive treatments which may improve or support other interventions.

The following section aims to provide the evidence for the effect of various pharmacological interventions on reducing incidents of challenging behaviours and/or core features of ASC such as repetitive behaviours. Thereafter, psychological interventions for people with ASC will be highlighted.

A randomised controlled trial (RCT) is considered a gold standard when looking at evidence for drug efficacy. The chapter makes it clear how little evidence of this standard exists in the literature. Clinical practice when working with people with ASC often extrapolates evidence from groups of people who do not have ASC.

Antipsychotic medication

Antipsychotic drugs are frequently used in all areas of psychiatric practice with the aim of reducing aggression and agitation. This is despite a limited evidence base for their efficacy. To date, there has not been a single RCT published which unequivocally supports their use in people with ASC. In one study over a third of 286 adolescents and adults with ASC had antipsychotic drugs prescribed for the management of challenging behaviours (Esbensen *et al*, 2009).

The effects of risperidone (Hellings *et al*, 2006) and haloperidol (Remington *et al*, 2001) in managing challenging behaviours have been studied with small and short-term RCT. There was a small but significant treatment effect supporting the use of risperidone over placebo in reducing aggression. Side effects were common but mild, with weight gain and sedation the commonest side effects recorded. There was also a very limited evidence for risperidone in reducing some of the core symptoms of autism, namely repetitive behaviour.

These studies have been short in duration with small numbers treated. The measures used to look at reduction in symptoms may not reflect any real life changes for carers and people supporting people with ASC, or the person's challenging behaviours.

Antidepressant medication

People with ASC experience a range of difficulties from anxiety, depression, obsessive thinking, compulsive behaviour and repetitive thinking. These may all be amenable to pharmacological interventions with antidepressant drugs.

Many antidepressant drugs have licences based on studies in non ASC populations for treating anxiety, depression, obsessive-compulsive disorder (OCD) and eating disorders. Their use in people with ASC is mostly based on the evidence from the original studies used for obtaining the drug licence and subsequent trials.

Antidepressants are a mixed group of drugs which can be conveniently split into a few main classes based on their structure or their action.

The oldest class of antidepressants are tricyclic antidepressants (TCA). They include amitriptyline, imipramine and clomipramine. Tricyclic antidepressants are used less today due to their side effects. People frequently experience a range of side effects such as dry mouth, blurred vision, constipation, sweating and urinary retention. They are also dangerous in overdose and can cause problems with heart rhythm.

The other main class of antidepressants in use today are selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine, citalopram and sertraline. These are less likely to cause side effects and are better tolerated than TCAs.

There are a number of other drugs that have similar actions to tricyclics or SSRIs, but do not belong to either of those classes of drugs. These include mirtazapine, venlafaxine and duloxetine.

There has been a single RCT looking at the effect of clomipramine versus placebo (Remington *et al*, 2001) and one looking at the effect of fluvoxamine (an SSRI) versus placebo (McDougle, 1996) on reducing core autistic features in adolescents. Not only was clomipramine very poorly tolerated, with 34% of participants dropping out before the end of the trial, but there were no difference between it and placebo in reducing any core autistic features. The study using fluvoxamine was small and the measure used was not designed for people with ASC. It demonstrated a reduction in repetitive behaviours and was well tolerated. Other studies using SSRIs showed similar results.

Anti-anxiety medication

Many studies have suggested that anxiety is nearly always a co-morbid feature for people with ASC (Bellini, 2004). It would, therefore, appear to be a sound rationale to treat anxiety in people with ASC due to the universal nature of this, however there is no current clear evidence for efficacy. Buspirone has been effectively used in the general adult population to reduce anxiety. There have been studies in children with ASC, but with no clear support for their use from the trials.

Anti-epileptic medication

There are no current studies examining the effects of anti-epileptic medication on managing challenging behaviour in adults with ASC, but there are some studies looking at children.

Anti-epileptic medication is used for treating epilepsy and bipolar affective disorders. These drugs are often described as mood stabilisers and have been frequently prescribed in the absence of bipolar affective disorder in an attempt to help manage emotional regulation difficulties. They have also been prescribed to treat children and adults who have ASC to help manage challenging behaviours.

The two drugs that have been studied with RCT in children are sodium valproate (Hellings *et al*, 2005; Hollander *et al*, 2010) and lamotrigine (Belsito *et al*, 2001). There are no consistent benefits from using these drugs in reducing challenging behaviours in children with ASC and if this is extrapolated to adults, there remains no evidence for their use.

Stimulant medication

Hyperactivity symptoms are very common in people with ASC, with up to 14% receiving active treatment for them (Langworthy-Lam *et al*, 2002). Methylphenidate is the commonest drug used in the UK to treat ADHD. It has a license for treating children and adolescents, but is used frequently to treat adults who continue to have symptoms after treatment as adolescents. It is a controlled drug due to its potential for misuse.

There are currently no studies to support the use of methylphenidate in adults with ASC. There is only one study at present in children, which

suggests a modest reduction in hyperactivity but no change in core autistic features (RUPP, 2005). Methylphenidate was associated with irritability in up to 20% of those in the study. It is difficult to extrapolate these figures to adults, but a trial of a stimulant drug in an adult with ASC and hyperactivity where ADHD is confirmed is worth pursuing.

Hormonal medications

People with ASC have been treated with a range of hormones to try to support behavioural management. The clinical rationales for these are often tenuous, using animal models as a basis. Niesink *et al* (1983) suggested that when the adrenocorticotropic hormone (ACTH) was administered to rats it led to less disturbed behaviour when their environment was disrupted. The two RCT which have been conducted show either no change in behavioural measures (Buitelaar *et al*, 1996) or a very modest effect on social isolation (Buitelaar *et al*, 1992)

An animal study (Charlton *et al*, 1983) showed that secretin, a gastrointestinal hormone, has effects on the central nervous system, and has led to recognition of the increased incidence of gastrointestinal disease in people with ASC (Horvath & Perman, 2002) and it being trialled in altering core symptoms of ASC. An open study suggested some improvement in social, communication and cognitive functions in a number of children who received secretin during investigations for gastrointestinal problems.

Oxytocin is another hormone which has been studied with an aim to reduce core autistic features. Oxytocin is more commonly associated with pregnancy and is used to induce labour. Some studies have suggested it plays a role in reducing anxiety levels (Andari *et al*, 2010). Four small studies with a RCT crossover design have compared oxytocin to placebo in adults with ASC. These studies have examined any possible effect in reducing repetitive behaviour and enhancing social behaviour. There appeared to be a small effect on reducing repetitive behaviours in adults with ASC and an improvement in some aspects of communication.

Oxytocin is broken down very quickly in the body and is generally given by continuous intravenous infusion, although it can also be given by intranasal spray. Its use is associated with a wide range of side effects. This makes it an impractical drug to use for people with ASC.

Melatonin is a hormone that has been used in children with developmental disorders to help with insomnia (Wheeler *et al*, 2005). There are no RCTs to support its use, but some children with ASC appear to benefit from it to help with sleep disturbance (Paavonen *et al*, 2003).

Other drug treatments

Adults with mild dementia have been increasingly treated with a group of drugs aimed at reducing the problems associated with memory loss. This includes drugs known as acetycholinesterase inhibitors. These drugs appear to, for a short period of time, slow down deterioration associated with Alzheimer's disease in its earlier stages.

The drugs have been used in adults and children with ASC to try to improve some aspects of cognitive function. There have been two trials; one comparing donepezil with placebo (Erickson *et al*, 2007) and one of galantamine versus placebo (Nicolson *et al*, 2006). There was no evidence of any benefit in these two trials. Side effects were also common.

Psychological interventions for mental health problems

Psychological treatments of co-morbid psychiatric disorders are widely regarded as a necessary adjunct to psychiatric and medical interventions (Gillis & Beights, 2012). From a psychological perspective, it is argued that individuals with ASC will struggle to interpret the world around them due to inherent difficulties associated with the triad of impairments. This can lead to social isolation and social challenges, in turn triggering high levels of distress that may further evolve into anxiety disorders, depression or challenging behaviour. Epidemiological studies suggest high prevalence rates of psychiatric disorders already in children with ASC (Filipek *et al*, 1999; Green *et al*, 2000). Some studies suggest that approximately three-quarters of children with an ASC, particularly those who are described as 'high functioning', meet criteria for at least one co-morbid DSM-IV-TR disorder (Mattila *et al*, 2010; Simonoff *et al*, 2008). Other studies show that about half meet the criteria for two co-morbid disorders (Gillberg & Billstedt, 2000; Leyfer *et al*, 2006). Co-morbidity was most frequently found in the areas of oppositional defiant disorder (7–28%), anxiety disorders (11– 84%, with the most frequent co-morbid disorders including

specific phobia, obsessive-compulsive disorder, social anxiety disorder, and generalised anxiety disorder), sleep disorders (34–60%), and attention deficit hyperactivity disorder (28–31%; Bradley *et al*, 2004; Leyfer *et al*, 2006; Mattila *et al*, 2010; Simonoff *et al*, 2008; White *et al*, 2009).

Increased support can be found specifically for adapted cognitive behavioural interventions when treating mental health problems in individuals with ASC (eg. Sze & Wood, 2008; Wood *et al*, 2009). Cognitive behaviour therapy (CBT) was originally developed by Aaron Beck and is based on the premise that individual experiences shape a person's core beliefs, which acts as the guiding rule governing the person's cognitions, behaviours and emotions, which are in turn inter-dependant (Beck *et al*, 1979). In cases of mental ill health, the cognitive behavioural practitioner endeavours to support the patient to alter their behavioural responses and cognitive appraisals in order to alleviate the emotional distress associated with the situation, alter the patient's thinking and eventually re-structure their core belief system (Beck *et al*, 1979). This type of therapy often uses concrete learning examples and people with ASC usually benefit from the structure of this approach.

Adaptations of CBT for children with ASC are described in detail by Moree and Davis (2010) and it may be suggested that these can be valuable when working with adults with ASC and mild intellectual disabilities (Gillis & Beights, 2012). The authors propose the following steps to treatment: (a) developing disorder-specific hierarchies (ie. addressing skill deficits associated with ASD that are prerequisite to implementing CBT); (b) using concrete visual aids (a practice commonly used in educational and behavioural interventions for children with an ASC); (c) using the person's specific interests to assist in developing rapport, engaging in the treatment process, and building motivation; and (d) including carers in treatment sessions (which may increase the likelihood of generalisation).

A clear benefit of CBT is the empowerment of the individual to use self-management approaches and build resources to empower the individual to learn skills for managing distress that will prevent relapse in the future. Good evidence for the effectiveness of CBT can be found with regards to the treatment of anger and aggression in people with mild intellectual impairments, such as suggested by Taylor *et al* (2005). Nevertheless, for individuals with lower level cognitive functioning, talking therapies and CBT may be less useful treatments. Gillis and Beights (2012) suggest that in the US the National Autism Centre (2009) identified a series of

'established treatments' for individuals with ASC including (a) antecedent packages (eg. incorporating choice, prompting, familiar stimuli, etc.), (b) behavioural packages (ie. applied behaviour analysis, behavioral therapy, and positive behaviour support), (c) comprehensive behavioural treatment for young children (sometimes referred to as applied behaviour analysis or early intensive behavioural intervention), (d) joint attention interventions, (e) modeling, (f) naturalistic teaching strategies (eg. incidental teaching), (g) peer training packages, (h) pivotal response treatment, (i) structured schedules, (j) self-management, and (k) story-based intervention packages (eg. Social Stories).

Individuals with ASC who have lower levels of intellectual abilities may further express the distress associated with mental disorder or difficulties with their social environments through challenging behaviour. Interventions for challenging behaviours in individuals with ASD are most commonly based on principles and procedures derived from applied behaviour analysis and positive behaviour support (Carr, 2007; Carr *et al*, 2002). This approach has received widespread regard particularly as research data to date does not show clear evidence of the effectiveness of psychopharmacotherapy for this presentation (Singh *et al*, 2011). Effective behavioural interventions are based on a functional assessment technology that enables researchers and clinicians to derive and test hypotheses about the functions of challenging behaviour in specific settings (Matson, 2009; Matson & Nebel-Schwalm, 2007). Interventions are then clearly aligned with the key functions of the challenging behaviour and may vary in scope, ranging from a single focus (eg. to eliminate aggressive behaviour) to multiple foci (eg. to eliminate aggressive behaviour, teach social interaction skills, and improve quality of life).

Conclusion

Pharmacological interventions are frequently used in people with ASC and there is a wide range of treatment options available. Evidence points towards the use of psychological interventions when addressing the mental health needs and issues of challenging behaviour in individuals with ASC. There is an expectation that prescribing psychotropic medication for all people should be evidence-based where possible. It is important for the reader to remember that a lack of evidence does not mean that different drugs may not work. It frequently reflects the difficulties and often expense in running trials in people with ASC.

Many people with ASC develop difficulties in their day-to-day living which are frequently disabling. Provided that medication is seen very much as an adjunctive treatment to other interventions, it can play a valuable role in helping people with ASC function better. This chapter has highlighted psychological interventions to support treatment of mental health problems in people with ASC and it has been suggested that people with higher level cognitive functioning can access cognitive behaviour therapies, while those with more severe levels of intellectual impairment may benefit from the use of applied behaviour analysis and positive behaviour support strategies. Side effects are common with most of the medications and careful consideration when prescribing and monitoring will help with optimising treatment. When medications are prescribed for people with ASC it is important that they are reviewed regularly and critically to assess any benefits and risks, as increasingly people are left with multiple prescriptions with no identifiable benefits. It is suggested that a favoured approach to treatment combines the use of psychological interventions with psychopharmacological treatments.

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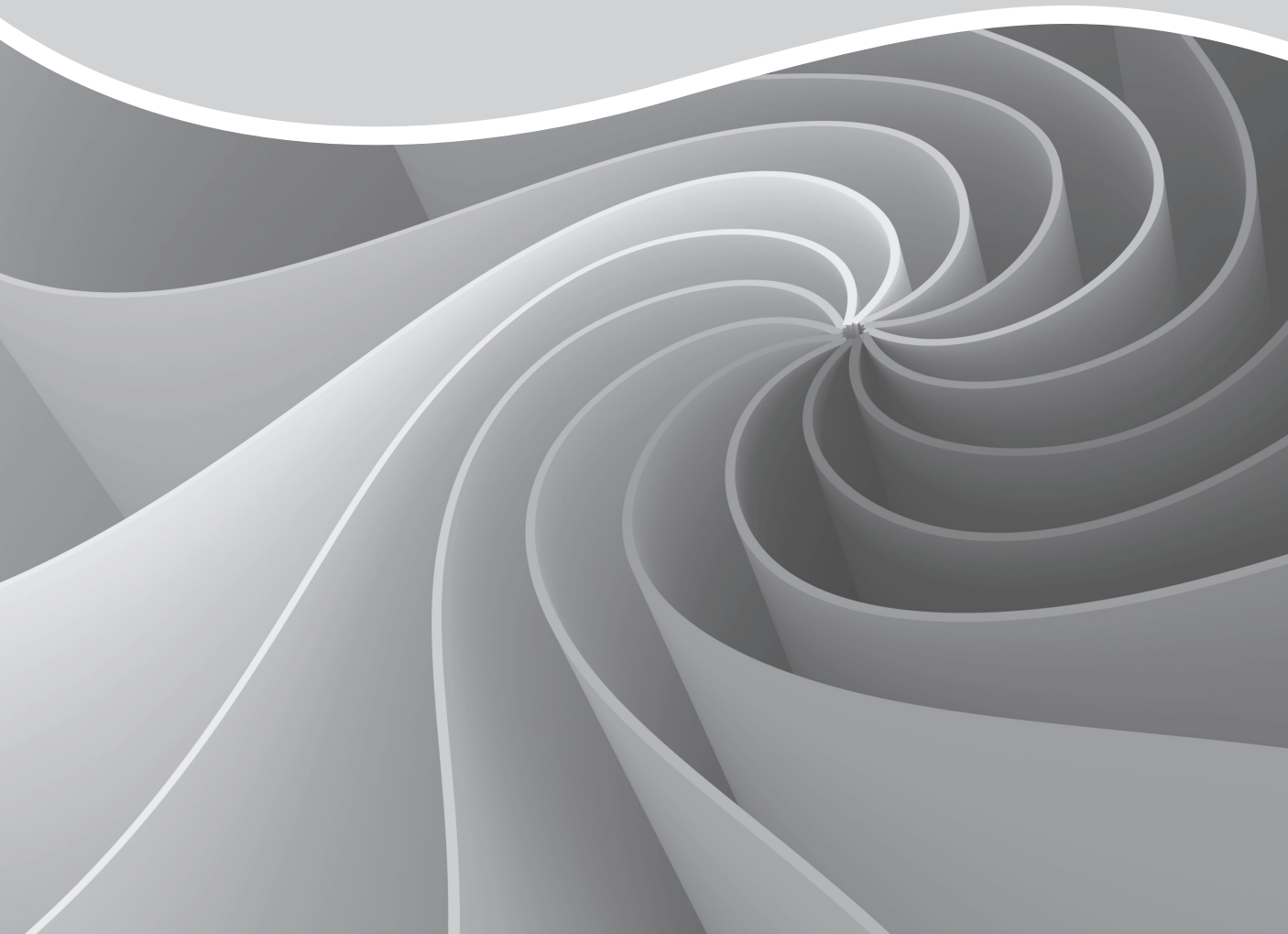
Part 2:

Service development and transition in the context of current legislation and policy



Chapter 4:

Legislation and policy

Nick Walsh and Ian Hall

Introduction

There are several important pieces of legislation that have a direct or indirect impact on people with autistic spectrum disorders (ASD), and the health and social care provided for them. This chapter will discuss relevant aspects of the Autism Act (2009) and *Fulfilling and Rewarding Lives: The strategy for adults with autism in England* (DH, 2010a), as well as other legislation that may be relevant to people with ASD, such as the Mental Health Act (1983) and the Mental Capacity Act (2005), all of which apply to England and Wales. Scotland has a broadly similar legal framework, although the specific legislation differs.

For Acts of Parliament relating to healthcare, there are usually helpful accompanying codes of practice, which provide guidance for professionals on how to interpret and apply the law. For example, for people in England and Wales there is a Mental Health Act Code of Practice (DH, 2008), which relates to the Mental Health Act (1983, revised 2007). The NICE guidelines for autism in adults will also be discussed in this chapter (NICE, 2012). In terms of government policy for health and social care, the Autism Act (2009), which applies to England, is perhaps the most important recent piece of legislation for people with ASD. This is because it led to *Fulfilling and Rewarding Lives: The strategy for adults with autism in England* (DH, 2010a), which is a statement of policy aiming to significantly improve the lives of people with ASD.

The Autism Act (2009) and strategy

The Autism Act (2009) was the first law to focus on the needs of people with a specific condition. The Act was designed to address the needs of adults with autism spectrum disorders across public services in England. The Autism

Strategy – *Fulfilling and Rewarding Lives: The strategy for adults with autism in England* (DH, 2010a) – was produced to spell out how this could be achieved in practice. The Autism Strategy fits with the government's plans to change the way public services are provided through its agenda of personalisation and work choice. It is hoped that social changes will follow from this and that people with ASD will have equal opportunity to access education and employment support; be able to choose where they live and to be part of social networks; have their health needs met appropriately; have access to a social care needs assessment; be able to live free from discrimination and, where they can be supported to, live independent lives.

The specific aims of the strategy relate to:

- increasing awareness of ASD among professionals
- establishing clear and consistent pathways for diagnosis in all areas
- enabling access to a personalised needs assessment
- improving access to services needed to promote independent living
- helping adults with ASD into work
- assisting local organisations to plan and develop services.

The government expects that these outcomes will be achieved by implementing existing policies more effectively and by adapting mainstream services, as required by the Equality Act (2010) which superseded the Disability Discrimination Act (1995).

One intended outcome of the strategy is to help adults with ASD access services more easily, as well as to increase referrals for diagnosis by increasing awareness and understanding of ASD. The strategy recommends that ASD awareness training is made part of generic equality and diversity training across the public sector, in line with the requirements of the Equality Act (2010). In health and social care, specialist training is recommended and organisations are expected to prioritise its implementation for staff, who are most likely to come into contact with adults with ASD, in particular those staff who perform community care needs assessments and clinicians whose role may affect people's access to services, for example GPs, who are likely to make referrals for diagnosis.

The strategy highlights how difficult it is for adults to get a diagnosis of an ASD. One aim of developing clear diagnostic pathways is to make it easier

to get community care assessments and carers' assessments. Under the NHS and Community Care Act (1990), local authorities must provide these. The guidance also makes it clear that these assessments cannot be denied because of a person's IQ. Furthermore, adults are entitled to an assessment even if they do not have a diagnosis of ASD.

The strategy relies on existing duties under the Equality Act (2010) to help support independent living. Adults with ASD are eligible for personal budgets and the strategy focuses on greater personalisation of services as a way of achieving these goals. Personalisation means giving people choice about the way social care is provided to them and includes the use of personal budgets and emphasises early intervention and prevention (DH, 2010b). Another important aim of the Autism Strategy is to increase employment rates among adults with ASD to promote social inclusion and reduce poverty. This relies upon expanding and adapting existing programmes for disabled people, as well as training for Jobcentre Plus staff. Part of the strategy describes the way organisations will develop local services. Information about the rate of ASD will be provided so that local organisations can estimate the level of unmet need. Adult social services departments are expected to appoint a joint commissioner/senior manager with responsibility for ASD and a 'lead professional' should be appointed in each local authority to develop diagnostic and assessment services for adults with ASD. However, the strategy does not guarantee a right to services, which depends on existing eligibility (FACS) criteria. Organisations must take into account the views of adults with ASD and their carers when developing services.

Local authorities and NHS bodies are expected to provide relevant information around ASD and to signpost people to organisations or charities that may be able to provide support. All adults should have access to a diagnostic service. To improve screening, early diagnosis and support, the National Institute for Health and Clinical Excellence has produced guidance on best practice (NICE, 2012).

Mental health legislation

The Mental Health Act (1983) (amended 2007) allows for people with intellectual disability or ASD in England and Wales to be detained against their will in a psychiatric hospital for assessment and treatment. This can only happen in certain circumstances. The detention needs to be:

- in the interests of the person's own health
- in the interests of the person's safety, or
- for the protection of other people.

Alternatives to detention need to be considered before someone is sectioned under the Act, including community assessment and treatment, and treatment in hospital with the patient's agreement. An important factor is the degree of risk involved to the person or other people. People detained under the Mental Health Act (1983; 2007) can formally appeal against their detention to the mental health review tribunal, which is an independent panel of a lawyer, doctor and lay person. The tribunal has the power to discharge the patient from the hospital.

ASD are defined as mental disorders within the meaning of the Mental Health Act (1983; 2007). However, the code of practice for the Mental Health Act (2008) makes it clear that detaining someone with an ASD in hospital is almost always undesirable (especially if they don't have another mental illness). This is because changes to routines and environment are extremely distressing to people with ASD. This is likely to result in further anxiety and distress for the person concerned. Additional support in a familiar setting is a preferable alternative. In order to detain someone on the basis of a diagnosis of ASD alone, there will almost always be evidence of 'abnormally aggressive and seriously irresponsible behaviour' (as stated in the Mental Health Act, 1983). The Mental Health Act (1983; 2007) code of practice (DH, 2008) gives guidance as to how this may be assessed. In general, people who are being assessed for detention for aggressive or irresponsible behaviour should be assessed by a consultant psychiatrist, with appropriate expertise in working with people with ASD, and have a formal psychological assessment. Ideally, this assessment would include professionals from a multidisciplinary team who have knowledge and experience of working with people with ASD and the team would seek the views of relatives, friends or carers. However, professionals should avoid inappropriately relying on them to make decisions on someone else's behalf.

When carrying out assessments on people with ASD, it is helpful for someone who knows the person being assessed to be present (although confidentiality must still be respected). Understanding how someone usually behaves and interacts with others helps professionals to avoid giving unnecessary medical treatment or detaining people inappropriately. Consideration should be given to the setting in which people are detained, so that their social

needs can be met. The requirement of the Equality Act (2010) to make 'all reasonable adjustments' still applies. However, this may not be possible in urgent situations or where the risk is very high. Steps should also be taken to support people to make decisions for themselves and to ensure that their rights under the Mental Health Act are protected. This may include, for example, providing support to help people decide whether and when to make an appeal against their detention under the Mental Health Act.

Mental capacity legislation

The Mental Capacity Act (MCA) (2005) refers to both everyday occurrences and decisions that could have a long-term effect for the person. The MCA starts from the premise that everyone has capacity unless proved otherwise. For those who do not, the Act is there to tell us who can make decisions on behalf of someone and how this should be done in the person's 'best interests', and so that the person is supported to make as many decisions for themselves as possible.

The five key principles of the MCA (2005) are:

1. Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.
2. A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
3. Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
4. Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.
5. Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

Case example

Amir is a 24-year-old man with an ASD who lives with his family. His brothers often used to tease him about passing smelly bowel motions, and as a result he used to try and avoid going to the toilet. Amir got very constipated and eventually had to be admitted to hospital with severe abdominal pain. There, he required a procedure under anaesthetic to

remove a build up of faeces. As a result of this, Amir developed a dislike of hospitals. A couple of years later he started to get upper abdominal pain. He refused to attend the GP surgery, so the GP visited him at home. The GP was very worried as Amir looked extremely pale and Amir said he had been vomiting blood. The GP wanted to admit him to hospital for investigations and a blood transfusion, but Amir refused to go because he did not like hospitals.

Commentary

According to the MCA (2005), in order for an individual to have the mental capacity to make a decision they need to be able to understand the information that is needed to make the decision. They need to be able remember the information long enough to make the decision, and to be able to use that information, weighing it up, to make the decision. They also need to be able to communicate the decision. If someone lacks the capacity to make a particular decision, then a decision can be made on their behalf in their best interests.

ASD can affect mental capacity in a number of ways. They can affect a person's ability to understand information relevant to a decision, particularly if the ASD is associated with an intellectual disability. In this case, even if the doctor explains things in an accessible way, Amir may not understand the likelihood that his stomach is bleeding, the basics of what a blood transfusion involves and its risks and benefits, and the fact that his life is in serious danger. If Amir does understand the information sufficiently, his ability to use the information may be affected by his ASD, as he may be extremely wary of new situations, and perhaps put too much weight on his previous aversive experience of hospitals, and insufficient weight on the risk to his own life. In medical decisions, the treating doctor needs to assess the patient's capacity to make decisions (they may take advice from professionals experienced in working with people with ASD), and if the person lacks capacity, the best interests decision needs to be made taking into account the views of those involved, particularly the person with an ASD.

Another important principle in the Mental Capacity Act (2005) is that all necessary steps should be taken to maximise a person's capacity. This means, for example, that the information needed to make the decision should be communicated in an accessible way, and especially for people with ASD, time should be given to adjust to unexpected or new situations.

Sexual offences legislation

People with ASD can find sexual relationships difficult and they can sometimes bring them into conflict with the law.

Case example

Harry is a 33-year-old man who has a diagnosis of ASD, and also has intellectual functioning in the borderline range. He lives with his parents. He has a strong interest in public transport and likes to spend his days taking rides on buses and trains. One day, he was using a urinal in the toilet at a railway station and a man approached him for sex. This happened quickly in the cubicle, and there was very little conversation between the two men. Prior to this, Harry had been wanting to have sex with another person for several years, and he found the experience enjoyable. Harry started to approach men for sex in other railway station toilets. He would do this by touching the buttocks of men standing at the urinal. Sometimes this resulted in him having sex in the cubicle, but more often it evoked a hostile response in the man, and on several occasions led to him being arrested by British Transport Police.

Commentary

In England and Wales the Sexual Offences Act (2003) is essentially consent and capacity-based legislation. People with ASD can sometimes struggle with empathising with potential sexual partners and therefore with ensuring that the partner consents. In this case, although Harry initially had a brief sexual encounter where both parties consented, in many of the subsequent encounters Harry did not establish consent, and the potential partners objected to his behaviour. The other men who sought to meet people in the toilets used eye contact and subtle body language to establish mutual consent, which Harry had difficulty noticing and using because of his ASD.

There are two other important factors in Harry's case. One was his vulnerability to assault and exploitation because of his behaviour, and the other that his family came from a cultural and religious tradition that strongly disapproved of homosexual behaviour. Educational interventions focused on him developing more appropriate ways of establishing sexual relationships that did not bring him into conflict with the law, and helped to protect him from exploitation

Conclusion

In England, the Autism Act (2010) and the subsequent autism strategy – *Fulfilling and Rewarding Lives: The strategy for adults with autism in England* (DH, 2010a) – have the potential to make a real positive difference to the lives of people with autism spectrum disorders. Key to this will be the widespread availability of diagnostic services, and other services becoming much better at making reasonable adjustments. However, the Strategy is being implemented by local health and social service organisations, and it remains to be seen how fully it will be implemented in each area.

When supporting people with ASD, it is crucial to be aware of people's ability to make decisions for themselves, and how an ASD might affect this in particular ways. There is specific guidance for health and social care professionals in the Mental Capacity Act code of practice to help support people to make decisions, and to take the best decisions on behalf of people who lack capacity. Although mental health legislation applies to people with ASD, its use is generally restricted to when people pose a significant risk to themselves or others. Even in these circumstances, it is important to consider alternatives to compulsory admission, as people with ASD can find the change in routine adds to their distress.

Like anyone else, people with ASD are subject to criminal law. Sexual offences legislation provides an example of how difficulties with social interaction can bring people with ASD into conflict with the law. Helping people to develop social skills can be crucial in addressing these conflicts.

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Chapter 5:

Autism spectrum conditions and services

Carol Povey

Introduction

With a prevalence rate of just over one in 100 (Brugha *et al*, 2009, 2011; Baird, 2006), and the establishment of the Autism Act (2010) and its subsequent strategy, the issue of how to enable people on the autism spectrum to live 'fulfilling and rewarding lives' (DH, 2010) has never been more pressing. This chapter describes what autism-specific, person-centred services and support for adults with autism look like and contains practical information on how to provide them.

Background

From a recent survey of 1,149 young people with autism aged 16–24, a third of respondents stated that they were not in receipt of education, training or employment (Bancroft *et al*, 2012). Almost half of adults with autism aged 25 and over live at home and almost the same number are dependent on their families for financial support (Higgins, 2009). This is a very different picture from people without autism – there remains a long way to go until people with autism are able to have the same opportunities afforded to people who don't have the condition.

There is very little research on outcomes in adult life (Howlin & Moss, 2012) and in particular for older adults as they move from middle into older age (Happé, 2012; Piven *et al*, 2011, Mukaetova-Ladinska *et al*, 2011) (for more about older adults see **Chapter 7: Autism spectrum conditions in later life**). While there is rather more consensus about what constitutes good practice in education (Charman *et al*, 2011), what services and support should look like in adulthood is a greatly under researched area (Shattuck, 2012).

Of the £25.5 billion that adults with autism are estimated to cost the UK economy, 59% is accounted for by services, 36% by lost employment for the individual with autism, and the remainder by family expenses (NAO, 2009). It is therefore vital, not only ethically and morally but also economically, to ensure that the services being delivered are enabling people to have the very best outcomes possible and are as focused on individual needs as they possibly can be. In most cases this means moving towards independence and where appropriate, employment, but always towards ensuring people with autism have access to opportunities to lead valued and fulfilled lives enabling them to live active lives as citizens within their community.

What should services for people with autism look like?

Lorna Wing once stated that 'once you've met one person with autism, you've met one person with autism' (2011) – an illustration of the heterogeneity of autism. It therefore follows that any service designed to support people with autism needs to be individualised and person-centred. People's needs also change throughout their lifespan, therefore it is vital that any package of support is flexible, reviewed regularly, and adapted as needs change.

In order to support someone effectively, it is vital to know them as an individual, not only the aspects related to their autism, but their personality, their environmental influences and their particular strengths and needs. Times of transition, whether that be from school to adult services, or the move into retirement, may increase anxiety and uncertainly for people with autism. This can lead to either a need for support, which has not previously been required, or an increase in the support required.

The SPELL framework

The SPELL framework has evolved from effective practice in The National Autistic Society schools and services, but its principles can be used across all services that support people with autism (Beadle-Brown *et al*, 2009). It has been designed to be able to be adapted to people's individual needs, rather than sticking rigidly to one way of working. The five key aspects of the SPELL framework are: structure, positive approaches and expectations, empathy, low arousal and links.

Structure

One of the key difficulties people with autism face is in understanding the world around them, particularly with regard to the behaviour and motivation of other people. Structure, routine and a level of predictability which helps the individual know what is coming next, the order of activities and when a task is finished, empowers people to be more independent and minimises anxiety (Siaperas & Beadle-Brown, 2006). Consistency of approach and a well organised programme of activities help people to feel confident and successful. This does not mean that life should be boring or that there should never be any spontaneity, but that unnecessary stress should not be imposed upon people by providing an unstructured or chaotic environment or programme of activities (Mesibov & Shea, 2010).

Positive approaches and expectations

Everyone needs to feel appreciated, stretched and valued for his or her strengths and contributions, and to feel that they are actively engaged with those around them. Positive approaches mean engaging people in meaningful activities where they are supported and encouraged to make real choices. Very often, to be able to do this people will need support in communicating effectively, both through language and augmented communication methods. A focus on the person's interests and passions rather than those areas in which they struggle is far more likely to lead to successful learning.

Empathy

People with autism spend a great deal of time, energy and effort trying to work out how 'neurotypical' people think, what their actions mean and how best to respond in an acceptable and appropriate way. Staff supporting people with autism need to be able to do the same, to be able to see things from the perspective of the person with autism, to listen to them and understand what may upset, confuse, excite or engage them.

Low arousal

Anxiety is an overriding emotion that is reported by many people with autism. A low arousal approach is one where the least restrictive approach is taken, where the environment is managed to lower the level of stress experienced by the person with autism, and confrontation is avoided – particularly in situations where the person is already experiencing high

levels of tension. The low arousal approach is not one of 'no arousal', where all stimuli are taken away, but one of purposeful calm.

Links

Effective links with family, friends and professionals encourage consistency across different settings. Good multidisciplinary working is vital, from diagnosis through to service delivery (NIASA, 2003).

Putting the SPELL framework into practice in service delivery

A good person-centred service which incorporates the SPELL framework will demonstrate a real understanding of the way autism impacts on the individual, and where the individual's needs and aspirations are responded to flexibly and creatively.

Language and communication

Staff need to be consistent in their approach, including their use of language. They should communicate clearly and effectively, adapting their use of language to fit the preferred communication style of the person they are supporting. Very often this will entail minimising the use of unnecessary and 'flowery' language. Communication should always be as clear, concrete and predictable as possible. People with autism may have difficulty in picking up inference, sarcasm or metaphors, and this may increase their anxiety. It is important that in supporting people with autism, the supporter spends time thinking about how their communication may be received.

Many people with autism take longer to process information. Therefore, it is vital that staff are patient and don't try to rephrase instructions or information which has not yet been processed. All too often well-meaning attempts to be helpful can cause the most anxiety.

Within the initial assessment, it is important to understand the individual way that the person communicates both their needs, and their emotions and feelings. Within each person-centred plan, there should be a section which explains the way that particular person prefers to communicate, and the most effective way of responding. Once again, it is the ability to make

the plan individualised, and then to ensure all staff are using the plan to ensure the individual has more power in their life, which is key to its effectiveness (Mansell & Beadle-Brown, 2004). Many people will respond to augmentative and alternative communication methods, including the Picture Exchange Communication System (PECS) (Bondy & Frost, 1994), interactive communication boards or signing. Any successful methods which have been used within the school or home setting should be transferred into the new setting, and staff trained in their usage. This includes idiosyncratic words, symbols or phrases which may mean a great deal to the person with autism, but little to strangers. This is where a full and detailed assessment in vital.

(Further information on the SPELL framework in relation to communication and interviewing is presented in **Chapter 12: Communication and interviewing**).

Responding to sensory needs

There is a growing recognition of the importance of sensory processing in the way people with autism experience the world around them (Dunn *et al*, 2002). Each individual is likely to have a sensory profile which is individual and distinctive. People may be hyper- or hypo-sensitive to particular stimuli such as sound, touch and taste, and that sensory profile is likely to fluctuate across environments and time, and according to their level of anxiety. Learning style will also be related to an individual's sensory profile (Grandin, 2006). Some people find it helpful to use simple aids to manage their sensory environment, such as wearing headphones (which may or may not be linked to music), wearing tinted glasses, removing labels from clothing or wearing weighted clothes.

Anxiety and stress

People with autism very often report stress or anxiety as being an overriding emotion, which they have to try to manage on an ongoing basis. Many rituals and routines are ways of trying to manage that anxiety. Therefore, before thinking of eliminating any ritual, it is important to understand its function. Levels of anxiety also fluctuate in response to environment, circumstances and mood. Therefore, it is important not to assume that if someone can manage a task one day, they can necessarily manage the same task another day. The environment and level of anxiety or stress they experience will impact on their level of functioning.

Visual supports

'I think in pictures. Words are like a second language to me … When somebody speaks to me, his words are instantly translated into pictures … One of the most profound mysteries of autism has been the remarkable ability of most autistic people to excel at visual spatial skills while performing so poorly at verbal skills.' (Grandin, 1995. p19)

For most people with or without autism, visual tools such as traffic lights, calendars, signage (eg. toilets, exit etc.) and maps help to orientate and reinforce rules which, for the most part, give a sense of understanding and security. This need for visual structure is more important in unfamiliar environments such as in a foreign country, where both language and culture are unfamiliar. There are very few of us who would not appreciate a clear map when negotiating an unfamiliar environment.

The use of visual aids enables many people with autism to make more sense of the world around them. This may take the form of a simple timetable with symbols through to complex schedules held on an iPhone. Whatever visual supports are used, it is important that they are appropriate to the individual. Visual supports can be particularly useful when introducing change, helping through a transition such as moving between different activities, going on holiday or the introduction of new or different staff.

Technology offers many opportunities to people with autism, enabling them to communicate and interact with others through social media, use individualised signs and symbols to make choices, and to use visual timetables. Research into the efficacy of computer-based interventions is still at a relatively early stage (Ramdoss *et al*, 2012), but many individuals with autism report that emerging technology is effectively opening their worlds.

Martin's story

Martin has difficulty predicting the future and coping with change, and living in a very chaotic family it was thought that this unpredictability had contributed strongly to his past offending behaviour. A full assessment of his needs was done and a service developed where there was a high level of structure and staff experienced in working with people with Asperger syndrome and high risk behaviours. Previously, Martin had not been expected to take responsibility for planning his day, running his home or taking care

of his own well-being, but through the person-centred planning process he had expressed that he wanted his own place, and a written agreement was made in which certain parameters of conduct were set, mainly based around abstinence from drugs and following a basic programme of activities.

Martin moved into his flat in June 2009, with staff who had been working closely with him and key staff within the low-secure ward where he had spent the past nine months. A number of strategies were put in place to manage Martin's anxiety, as he had a history of being both physically aggressive toward others and self-injurious when he became extremely anxious. This was done by developing a plan. The plan included how he could recognise when he was becoming anxious and what he could do to stop that escalation. It also involved physical exercise and the use of a card system whereby staff could present him with a yellow card and then red card if they felt the need to withdraw from him. This system avoids the likelihood of staff and Martin starting to engage in confrontational behaviour.

Martin enjoys playing games, so activities engaging staff in playing strategy games were included in Martin's programme, giving him an opportunity to get to know new staff. His interest in Central America was also developed through classes at the local college. Martin has sensory issues with temperature control (both heat and cold) and will not dress appropriately for the weather. A programme to enable him to choose appropriate clothes was developed and implemented, which relied on information from the weather forecast. Similarly, a programme focusing on him choosing whether to have baths or showers helped him to develop basic self-care skills.

Martin becomes very anxious around certain dates, such as Royal birthdays, events the Royal family are attending, visiting friends in hospital, his parents' birthdays etc, so staff ensured him that there was flexibility to change scheduled events in advance using a visual calendar. Martin is vulnerable in the community as he finds it hard not to approach members of the public who he feels are breaking the rules. Some work has been done to help him manage this using Social Stories, and he also carries an Autism Alert Card, which he feels may help him should he get into trouble when out alone.

Over a period of three years, the level of support required by Martin has diminished, and he is more reliant on his own structures to manage his own times and his emotions. He now uses an iPhone, where he can schedule

in his weekly programme and has emergency numbers of staff should he need reassurance or help when he is not receiving staff support. He attends college four days a week and plays bridge twice a week in a local club. When Martin is feeling anxious, many of his old behaviours re-occur, but he writes down the level of anxiety he experiences in his diary and keeps it to discuss with staff when he is next visited.

Assessment and service design

In order to design a service based around someone's needs, it is vital to undertake a thorough assessment, which then leads to a holistic plan of care and support for the person. Every effort must be taken to involve the person at the centre of this process, including using visual aids and technology for people whose communication skills present challenges. Families will also have valuable insights, which should be welcomed and integrated into the support design.

It is also important to note that behaviours and difficulties which may appear to have disappeared may re-emerge if the person is put under stress or becomes anxious, in particular by any move or transition. It is therefore essential not only to gather information about how the individual presents in the here and now, but to take a detailed history if at all possible. An assessment to develop an individualised service can be done in three parts: data gathering, needs assessment and support design.

First, data needs to be gathered covering a wide number of areas, in particular the way the person's autism impacts on them and any service developed around them. This data then needs to be compiled, analysed and developed into a narrative so that staff working with the individual can start to gain a full and rich picture of the person. It is unrealistic to expect support staff to wade their way through mounds of data, so the assessment of needs should be written in a way that is accessible to all staff and starts to 'bring the person to life', even before staff have met them.

The needs assessment is the basis of a support design, where the needs of the individual are translated into a picture of what the service will offer. This will include what activities the individual will be involved with, the characteristics and competencies of the staff who will be supporting them, what training staff will receive to ensure they are appropriately skilled to meet the person's needs, what the individual wants to achieve,

any risks associated with the delivery of the service, and how the person will be supported to monitor and evaluate their service. It is important that all such documents are written in non-clinical terms, as these should be working documents accessed by a wide range of people, including the individual with autism, their family and staff, who are unlikely to be familiar with clinical terms.

Increasingly, local authorities are moving towards a model of self-directed support, whereby individuals are given their own budget with which they can purchase their support. The white paper, *Our Health, Our Care, Our Say: A new direction for community services* (DH, 2006), signalled the government's intention to move towards '[giving] customers a bigger voice over the care they receive'. By 2013, all people receiving social care funding in order to meet their assessed needs are expected to have a personal budget (Routledge & Lewis, 2011). Individual community care needs are assessed by the local authority using a resource allocation system (RAS). The assessment will lead to an indicative budget being set which specifies how much the council suggests it will cost to meet the person's assessed needs. From this, a support plan needs to be developed (an example is given below). Not only will this describe what the individual wants to spend their time doing, and what outcomes they want to achieve, but how much it will cost. For many people with autism, who may have very individual and sometimes idiosyncratic profiles of abilities and needs, it is vital that they are supported to plan by someone who knows them well and understands the impact autism has on their abilities, strengths and levels of functioning.

David's plan

My plan will concentrate on supporting both me and my parents, while I am living at home. This will work towards supporting me to improve independence skills, gaining confidence and removing the anxiety and stress from both my family and myself. This part also includes details of the support that my mum needs as my carer and will support her to continue caring for me.

The second part of my plan will focus on the support I will need to live independently in my own flat when I have found it.

Table 4.1: David's plan			
Support	Details	Payment	Cost p/w
One-to-one support	Four hours of one-to-one support from the NAS on Wednesdays and Fridays between 18.00–20.00. This support will be provided at £18.68 (x4 = £74.72) and includes £10 travel expenses per session (two sessions).	Direct payment	£94.72
Stress-relieving activities	Tai Chi once per week. £40 total for eight sessions.	Direct payment	£5
Computer	£300 contribution toward purchasing my own computer. Use to help with budgeting and budget plans. Find recipes to cook with. Maintain social contact with friends. For staff to motivate. Enable my dad to work from home using his computer.	Lump sum One-off direct payment	£5.76
Gym for stress-relief	£44 per month membership (£528 per annum). Again, this will be of great benefit for me to relieve stress and maintain a positive sense of well-being.	Direct payment	£10.13
TOTAL	Using my indicative budget		£115.61
Carer's courses	Pottery and other craft activities/ courses. £60 for five weeks for three terms per year; total £180 per annum.	One-off lump sum Carer's direct payment	£3.46
TOTAL			**£119.07**

One-to-one support

This initial four hours of support will be there to support me with developing my independence skills while still living with my parents. My parents are very supportive. However, the dynamic of our relationship and the stress

this causes both my parents and myself means that I will benefit much more from outside support. These four hours will be to gain skills in cooking and daily living, emotional support and reassurance. This support will be divided into two sessions of two hours.

Stress-relieving activities and gym

While living at home, it is vital that I am able to vent the frustrations and stress caused by the anxieties of everyday living. This is to support both me and my parents, as often they can become exhausted when caring for me and my anxiety can often transfer to them, which has caused conflict within our relationship. Stress-relieving activities such as Tai Chi and going to the gym will be essential for me to unwind and in turn allow my parents to do the same. The exercise I get at the gym will also help to maintain a balanced and positive well-being that I believe will help to prevent outbursts of anxiety.

Computer

This support to purchase a computer will help me organise my life and set important routines that I otherwise find difficult to manage, especially when I often wish to use my father's computer, which he needs for work. This, again, can cause additional conflict within the home. I intend to use this computer to support me to find recipes for cooking, budget planning and as a motivational tool that staff can use to contact and share information with me. It will help me to further set a structure to my life through the use of planning tools and support me to maintain social contact with friends so I do not become isolated. The primary outcome is that it will enable my dad to work from home using his computer and relieve any stressful conflict this causes.

Leadership in autism services

Working with people with autism is immensely rewarding and appeals to people who have a natural, often insatiable, curiosity about how others think and experience the world. Nevertheless, some staff struggle to understand the difficulties (and strengths) people with autism experience in areas which may be instinctive to people who are not on the spectrum. Effective leadership in services means ensuring that there are opportunities for staff to be able to reflect on their practice, to continuously develop through learning and development, and have structured support to link theory and practice.

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Chapter 6:

Transition

Sarah H Bernard

Transition: 'The process or a period of changing from one state or condition to another' (Oxford Dictionaries, 2012)

Introduction

People with autistic spectrum disorders (ASD) are known to experience difficulties with transitions. These difficulties generally arise as a result of the anxieties created surrounding change and may be displayed in a variety of ways. Transitions might appear to be minor, occurring from minute to minute, hour to hour, or day by day, or more major transitions, such as moving from nursery to primary school, primary to secondary, and from children's to adults' services. When we speak of transitions for those with ASD it is generally in reference to the move from child to adult services and the accompanying planning that should take place in collaboration with the young person and their family or carers (DFEE, 1994).

The ideal situation is that any transitioning process is planned carefully in order to allow a smooth transfer from children to adult services, thus minimising the anxieties produced from changes (Stapleton, 2000). Unpredictable changes are more likely to cause distress and impact on mental health (Hopson, 1981; Emerson, 2003). Unfortunately, services continue to have discontinuity, creating concerns for both the young people and their families. Some of the transitional difficulties are inherent in the structural systems we have in place for health care, education and social care.

This chapter will primarily consider how transition from child to adult services impacts on children and their families and how transition can be planned. Strategies to reduce the risks of distress, anxiety and subsequent behavioural difficulties will be discussed. Suggestions for troubleshooting at times of difficulty will also be considered. Other transitions will also be discussed.

Types of transition

Major transitions

- Changes involving education such as home to nursery, nursery to school, primary school to secondary school.
- Term time and school holidays.
- Major, unexpected family events such as a new baby in the family, serious parental illness, bereavement, divorce. Grief should not be overlooked (Hollins & Esterhuyzen, 1997).
- Moving from child to adult services involves changes of daytime occupation, change of social care provision including social worker, respite care, changes of provision of physical and mental health care.

Minor transitions

- Transitions experienced on a daily basis such as changing clothes, going to school/college, moving from one situation to another.
- Changes of people involved with the young person, such as teachers.
- Weekday activities versus weekends.

Transition from child to adult services

There is a statutory obligation for transitional planning to begin at age 14. This should be in collaboration with the young person, their family, carers and the staff working with them. The point of a transition, which is a social structure, and heavily influenced by cultural factors, is when the child or young person leaves children's services and moves to adult services. In health and social care, this occurs at 18 years old, but children with a developmental disability do not leave full-time education until 19, many of whom will subsequently move onto college education. It is unfortunate that all these services change at one time, which is also a time of vulnerability for people with ASD (whether they have additional developmental disabilities or not) because of a protracted period of emotional upheaval during adolescence and early adulthood (Morris, 1999). The rationale for changing health and social care at 18 years old, while reinforcing the fact

that these young people are moving into adulthood, also means a change of commissioning processes and the inevitable stresses surrounding allocation of resources and budgets. This, in addition to children with ASD reaching the age of consent at 18 years of age, in theory, thus taking charge of the plans for their life, adds to stresses for the family, who are frequently not ready to move on at the same time that services feel is appropriate for their young person.

There is a fundamental need for transitional planning to start early, be well co-ordinated and to ensure a smooth move into adult services (DH, 2004). An inadequate and poorly planned transition increases the risk of mental health and behavioural problems (Blancher, 2001; Carpenter & Morgan, 2003). It is important that the young person, if possible, is involved with any plans for their transition (Collins, 1994). In reality, the ride is bumpy, with fragmented services, poor communication (Routledge, 1998) and last minute decisions resulting in much stress for young people and their families (DfES, 2003). Placements risk breakdown because of inadequate planning and support (Raghavan *et al*, 2006).

An ideal transitional plan should include the following:

- early identification of needs including health, social care, education and leisure needs
- a holistic approach to the needs of the young person
- involvement of the individual
- inclusion of family wishes
- consideration of cultural issues
- risk assessment.

(Kobasa *et al*, 1982)

The possibility of transitional services should be carefully considered with staff; spanning adolescence into early adulthood ie. 16–25 years of age. This will ensure consistency at a time of other changes. Imaginative planning from services reduces stress for the child and the family and the risk of behavioural disturbances in early adulthood (Raghavan & Pawson, 2010).

Practicalities

Good practices rely on a number of practical factors:

- a person-centred approach (DH, 2009)
- clearly documented multi-agency pathways for transitional planning with collaboration and co-operation between agencies (DfES, 2003; DH, 2008)
- clear lines of accountability and responsibility with the identification of a key worker who co-ordinates the plans
- appropriate provision of services in adolescence and early adulthood which are responsive and proactive
- accessible inclusive services including primary care
- risk assessment and management
- sufficient resources including workforce and budgets; specialist commissioning for rare and/or highly complex needs
- accountability and measurable outcomes.

Troubleshooting

While the aim of services for young people with ASD must be to provide excellence in transition from child to adult service provision, it is inevitable that there will be times when the ideal is not achieved. Breakdown of the process is more likely in the following situations.

- Good practice guidelines are not adhered to. This arises for many interrelating reasons. The likelihood of this occurring may be reduced by ensuring an appropriate multi-agency forum is in place to consider the development and review of pathways, processes and responsibilities.
- Short-term crisis intervention is not likely to offer the best provision of services or expert care. The majority of crises are predictable. Good planning should ensure that services are appropriate and accessible at the time of transition. In general, lack of planning results in inadequate and poorly planned care, which increases uncertainty for the individual, their family and the professionals working with them. This in turn increases the risk of challenging behaviour or mental health problems.

- Failure to recognise risks or minimisation of known risks may result in inadequate and under resourced service provision. Risk assessment is an essential component of transitional planning and must be an ongoing part of assessment and management of the young person.
- The global level of functioning of the young person underpins an understanding of their needs (Taylor & Seltzer, 2011). This is particularly important for those with high-functioning autism or Asperger syndrome. The needs of this group of young people are often considered as being provided by child developmental disability services but, on reaching adulthood, service responsibility and provision is variable.

Case vignette

The ideal situation

James is a 17-year-old adolescent who has ASD and severe intellectual disabilities (SID). He lives with his highly supportive and nurturing parents, who are both teachers, and his sister who is 15 years old and attends the local grammar school.

James has been a pupil at a specialist school for children with ASD and intellectual disabilities since the age of five. He moved into the college, which is part of the school, at 16 years of age. James has 10 nights of respite care per year.

James has displayed a range of challenging behaviours including self-injury and aggression towards property. These behavioural problems have been assessed by the child and adolescent mental health services (CAMHS) and James fulfilled diagnostic criteria for attention-deficit hyperactivity disorder (ADHD) in addition to ASD. His behavioural problems were compounded by SID.

James has a comprehensive behavioural program, which is overseen by a clinical psychologist. The behavioural approach is consistent between home, school and respite care. James is also treated with methylphenidate, which is monitored by CAMHS.

Transitional planning started at 14 years of age. The family first met with the transitional worker from social care to consider James' needs and the views of the family. Options discussed included James remaining at home but attending the local special needs college of further education, where he would study daily living skills and horticulture. Respite care would move to an adult resource with weekend stays being offered in order to help James gradually move from his parents' full-time care. The option of a residential college was also considered, but not felt to be appropriate for him.

All agencies involved with James contributed to his transition plan. Adult psychiatric services for people with intellectual disabilities were informed that James would need ongoing mental health support. A meeting when James reached 16 years of age confirmed that the plans remained acceptable.

Currently, a college place has been identified for James once he reaches 18. A respite care service has also been identified and James will visit it from 17.5 years old. His school is planning a leaving celebration for a small group of children in his class. Adult psychiatric services plan to meet with CAMHS when James is 17.5 years old in order to facilitate a smooth handover of care.

Examples of how it could have been different

- James moved into a foster placement at 15 following the death of his father. His mother could not manage him at home.
- James moved from school to another college provision at 16 as his school could not manage his behaviour.
- The local CAMHS were not commissioned to see children with SID. James was seen by a tier four service which was many miles away from where he lived.
- Consistency and continuity were difficult to achieve because of a lack of local experience in behavioural management.
- James's mother was not able to manage James at home post 18 years of age.
- There were uncertainties about whether James might remain in his foster placement at 18 and alternative options had not yet been identified.

Clearly, the examples are extremes. The vignette is what an ideal transitional pathway should look like, with agencies supporting the young person and their family in order to best meet needs. The second account demonstrates, as a result of avoidable and unavoidable factors, how the situation becomes far from ideal, with it inevitably impacting on James and increasing the risk of distress, anxiety and behavioural problems. (In **Chapter 10** a carer's perspective of transition to adult services is given.)

Conclusions

Transition is a time of anxiety and potential distress for young people, their families and their support networks. Services should ensure that they have well-developed care pathways which proactively address and provide for the multi-agency needs of young people from 14 years to early adulthood. Poorly thought-out services increase the risk of the development of behavioural and/or mental health problems around the time of transition, which inevitably places further demands on services and, more importantly, increases distress for young people and their families.

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Chapter 7:

Autism spectrum conditions in later life

Ian Stuart-Hamilton

Introduction

Until very recently there was little research on autism spectrum conditions (ASC) in people older than their late twenties (Stuart-Hamilton & Morgan, 2011). Although this is changing, studies of ASC in later life are still rare. For example, at the time of writing (February 2012) a search for 'autism' and 'old age or ageing' as major subjects in *PsycINFO* gives a total of six results (compare that with 14,776 results when using 'autism' alone). This reflects the paucity of everyday knowledge of the condition among clinicians and other practitioners. One study (conservatively) estimates that in England alone, 864,000 middle-aged and older adults with ASC remain undiagnosed (Stuart-Hamilton *et al*, 2010). This lack of knowledge is probably attributable to ASC being a relatively recently discovered condition, and initial research has concentrated on the first generations of children to be identified with the condition. Older adults can only be identified retrospectively, and it is possible that many older adults with ASC have not sought re-diagnosis.

Of the research on older people with ASC that exists, some is about their participation as members of groups of people with intellectual disabilities of mixed aetiology. Such studies, although useful in other respects, are of little value in the context of this chapter. Other studies are more relevant to our needs, however. In the main, research has indicated that ASC in later life is a continuation (sometimes with modifications) of ASC as it is known in children and adolescents. For example, Kanai *et al* (2012) found that in young and middle-aged adults with various forms of ASC, performance on the Wechsler Intelligence Scale 3rd edition (WAIS-III) followed the expected hierarchy. Thus, adults with Asperger syndrome outperformed

those with pervasive developmental disorder not otherwise specified (PDD-NOS) and high-functioning autism in measures of vocabulary, information and comprehension, while high functioning autism participants had significantly lower scores on digit-symbol coding and symbol search than the Asperger syndrome and PDD-NOS groups. Generally, the evidence supports the argument that in cases of ASC with intellectual disability, cognitive skills remain depressed in adulthood (Billsted *et al,* 2007).

Brugha *et al* (2009) demonstrated that the incidence of ASC in the population appears to be relatively constant throughout life (though with a slight decline in proportions in the very oldest groups). Health and socio-economic problems are just as high in later life as among young adults with ASC (Stuart-Hamilton & Morgan, 2011). Interviews with younger and middle-aged people with higher-functioning ASC typically generate a similar set of findings: a litany of problems with daily living exacerbated by a depressing lack of awareness by employers, work colleagues and the medical profession alike (Stuart-Hamilton *et al*, 2010). Also, caregiver stress does not get better, and is likely to be very high among parents of adults with ASC, exacerbated as it is by the carers' own increasing frailty and possible financial vulnerability created by very long-term caring (Dillenburger & McKerr, 2009).

At a neurological level, although evidence is as yet sketchy, the available findings suggest that after an initial overgrowth of brain tissue in infancy, ASC in later life might be marked by a more rapid rate of decline or even degeneration in brain tissue from middle age onwards (Courchesne *et al*, 2011). However, as seen, these changes do not necessarily manifest themselves as significant changes in behaviour and intellect.

The following vignette illustrates the problems faced by a prototypical person with high-functioning ASC.

Vignette: Elizabeth

Elizabeth has a good set of qualifications in accountancy. She is almost preternaturally gifted at analysing complex financial systems and identifying how each section interacts with another. She should accordingly be destined for a glittering career, but instead she has had a succession of temporary jobs with long stretches of unemployment in between. When in a job, colleagues note how she 'fails' to join in any sort of social activity, and her line manager becomes exasperated because she doesn't understand 'basic phrases' such as idioms. Elizabeth has sought help from the medical profession. One GP said that ASC was 'something that kids get, isn't it?' and another said she couldn't possibly have ASC because she laughed at one of his jokes. Social services and Jobcentre staff seem either unwilling or incapable of helping. Because Elizabeth is clearly intelligent and has no physical disabilities, they find it impossible to understand that she might need specialist help. Elizabeth feels that she 'falls between the cracks' in the care system.

The examples are all taken from real sources and although Elizabeth is fictitious she is, sadly, all too typical of a person with high-functioning ASC. Imagine, therefore, what life must be like for someone with ASC and intellectual disabilities.

An especial cause for concern is the spate of recent studies reporting that in adults with intellectual disability in general, there appears to be an above-average rise in cases of dementia in later life (eg. Strydom *et al*, 2009). In the specific case of ASC, Tsakanikos *et al* (2011) suggest that dementia is more prevalent in women (in men, personality disorder and schizophrenia were commoner). There is, however, a serious danger of (mis)identifying co-morbidity in older people with ASC (or indeed other types of developmental disability), since shared symptoms are not indicative of shared causes. To explain why, we first need to examine the effect of neurotypical ageing on intelligence.

The majority of neurotypical people show a decline in intellectual skills in later life. Some aspects of this can be remarkably severe – older people's performance on some basic mental skills can be a standard deviation or more below the mean of younger adults' scores (see Stuart-Hamilton, 2012 for a review). Such a decline can be at least partially offset in neurotypical older adults by means of mental strategies and heuristics that compensate for this loss in more basic processing power (eg. Charness *et al*, 2001).

Therefore, the overall effect of intellectual decline in neurotypical older people is ameliorated. However, this same change could have a catastrophic effect on the majority of older people with ASC and intellectual disabilities, who are already functioning two or more standard deviations below the mean (de Figueiredo, 2010) and who perhaps lack the mental heuristics to compensate for their loss.

This loss could be so pronounced that an individual's new level of function could be on a par with a person with dementia. However, just because older people with ASC and intellectual disability are *functionally* indistinguishable from people with dementia does not mean that they *have* dementia. Dementia in a previously neurotypical person is the result of atrophy of neural tissue in the brain. A decline in intelligence in a person with intellectual disabilities in later life is unlikely to be due to atrophy of the same nature as dementia. Although, as we have seen, there is evidence for cell loss in the brains of older people with ASC, there is as yet no evidence of loss on the scale of dementia.

This might sound like an arcane point to be making, but it is potentially very serious. There are drug treatments available for dementia, but their effects on the brains of people with ASC are, to the best of this author's knowledge, unknown. Suppose that we identify an intellectual decline in older people with ASC and intellectual difficulties that is functionally equivalent to a decline into dementia. Do we give them a drug treatment, or withhold it? The dilemma is illustrated in the following vignette.

Case study: Peter

Peter is a 70-year-old man, diagnosed in his fifties as having ASC. Prior to that, he had been misdiagnosed as having schizophrenia, resulting in long-term drug and behavioural treatments that were distressing to him. Recently, his intellectual condition has deteriorated to the point where he has been referred for re-assessment as he seems incapable of coping with living in sheltered housing. He has become far more forgetful, and people who know him well have commented that he seems far less able to understand even basic instructions or requests.

Peter certainly needs help, but what is the cause of this change? It could be the result of a relatively normal senescent decline, or possibly he is showing the early signs of dementia. Note that we cannot rule dementia out, nor should we. The sad fact is that signs of dementing change in older people

with intellectual disabilities are often discounted or downplayed (Hassiotis *et al*, 2003). But the symptoms do not indicate dementia beyond doubt and giving unnecessary drugs to Peter (whose brain has already endured years of incorrectly administered anti-psychotic medication) could worsen his health and quality of life.

Matters would be made easier if there were a body of diagnostic measures that could be used, but there are no utterly reliable tests available. Although there are measures available to assess dementing change in people with intellectual disabilities (see Kirk *et al*, 2006), many are not necessarily appropriate (see Perkins & Small, 2006) and typically measure functional change. Furthermore, behavioural changes in people with intellectual disabilities diagnosed with dementia are similar to those in people without an intellectual disability (Duggan *et al*, 1996). Although the incidence of dementia is known to be genuinely higher in Down's syndrome (McCallion & McCarron, 2004), in connection with a genetic malformation held in common with a relatively rare form of Alzheimer's disease (Schweber, 1989), the evidence on other forms of intellectual disabilities (and ASC) is unknown, and extrapolating from one form of intellectual disability to another is a very risky procedure.

Conclusion

Research on ASC in older people is still very much in its infancy. The available evidence indicates that in later adulthood, the problems and pitfalls of having ASC remain and that quotidian activities, such as remaining in employment, are problematic. A repeated complaint of older people with ASC is a lack of understanding from others and a failure of the care system to cope with their needs. In people with ASC and intellectual disabilities, there is a very grave danger that intellectual decline in later life could be wrongly diagnosed as dementia, leading to unwanted and possibly damaging treatments.

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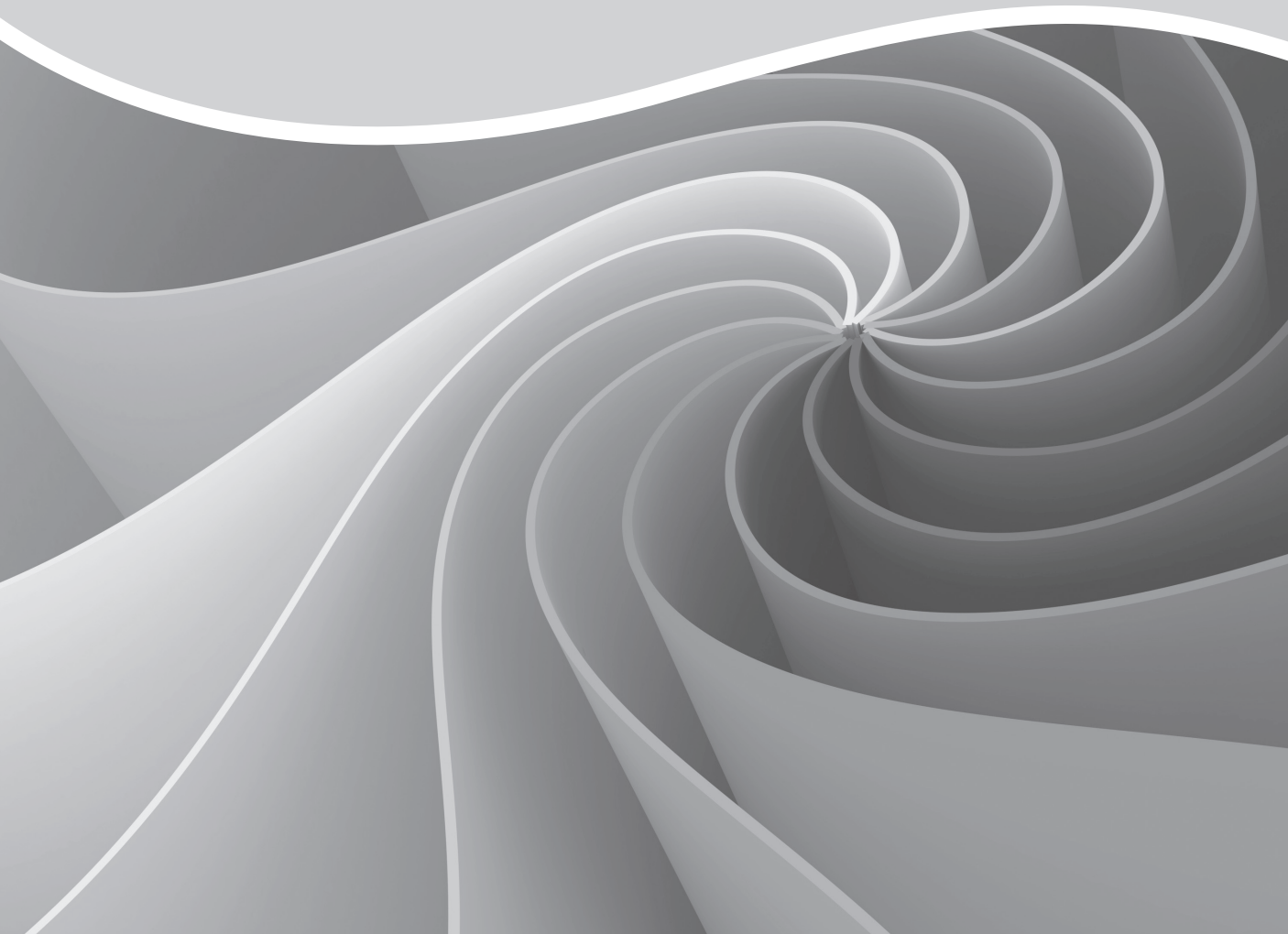
Part 3:

Issues of diversity and personal experiences



Chapter 8:

Diversity and autism spectrum conditions

Prithvi Perepa

Introduction

Autism spectrum conditions (ASC) are prevalent in all communities and ethnic groups, but is the interpretation of the condition and the experiences of people on the spectrum and their family members necessarily the same? Although multicultural societies are becoming increasingly the norm, there is very little research about the experiences of families belonging to the different cultural groups affected by autism and their expectations of services and required support. This chapter aims to provide an insight into some of these experiences and provides issues to consider when supporting people on the spectrum or their family members who belong to a minority ethnic community.

According to O'Hagan (2001), a cultural group is one where a group of people have a distinctive way of life based on common values, religion and language. This group identity could lead to people having not only distinctive views about various issues, such as autism, but also having specific needs to suit their own situations. In a multicultural society like the UK it is crucial to have an understanding of the attitudes, values and beliefs held by the different ethnic groups so that professionals working with individuals and families from the various communities are able to provide the required support.

Prevalence rates

Although rates of ASC are supposed to be the same across all ethnic groups, not all research conducted in this area suggests that this is always the case. Some studies have mentioned that there is a high proportion

of children from immigrant communities who are being diagnosed with autism (Goodman & Richards, 1995). On the other hand, a study conducted by Croen *et al* (2002) found that there is under-representation of people from minority ethnic communities with autism. Statistics of students on the autism spectrum within British schools on the basis of ethnicity show that the picture is not clear and there seems to be both over and under-representation of various ethnic groups (Corbett & Perepa, 2007). This, along with the varying rates in different countries, highlights that in spite of the assumption made by professionals, the incidence of autism spectrum conditions does seem to differ on the basis of ethnicity.

Due to the limited research on the subject, it is difficult to pinpoint the reasons for these varying prevalence rates. It could be that the difference is because of some biological or genetic differences within the various communities. However, as the same ethnic groups seem to have different rates of incidence in various countries, it is also possible that the difference is not entirely physiological but as a result of the procedures followed and tools used to make a clinical diagnosis of ASC. This would not be impossible as unlike some other disabilities, ASC are primarily diagnosed on the basis of observed behaviour. Therefore, the cultural values of the professionals can influence how they interpret a given behaviour. If that is the case, then further research is required to assess the effectiveness of the diagnostic tools in relation to various ethnic groups and how the results can be interpreted. In fact, Lindsay *et al* (2006) have suggested that the smaller number of children with autism in certain communities could be a result of professionals' inability to differentiate between issues of having English as an additional language from features of speech and communication delay. This could be reduced by use of interpreters, but it has been reported that the interpreters themselves had limited understanding about the condition and were unable to explain it. Therefore, it is important to use trained interpreters who understand autism and have an understanding of the person's culture. It is also important that professionals invest time in understanding what are the cultural norms for the family and use these at the point of diagnosis as well as when providing interventions.

Another possibility is that the features associated with the autism spectrum are not viewed as being different or part of a disorder in all cultures. This is not to deny that the strengths and difficulties associated with the condition are present among some individuals in all cultures, but that these differences may not always be classified as a disability that requires specific interventions. To explore this further, it is important to get an insight of how autism is understood in various cultures.

Understanding of autism spectrum

Many languages do not have a word to describe autism; could this be an indication of the social construct of the condition? Even so, when these communities are living in a different country to their country of origin it is likely that the government and voluntary organisations try to provide these communities with information about ASC. It has been noted that translated material which is provided to families from minority ethnic communities may be using inappropriate terms (Perepa, 2002). Some translated information also makes assumptions that the journey of autism has been the same in all communities. For example, the notion of 'refrigerated mothers' as the cause of autism may not have entered the discussion around the causation in certain cultures. Therefore, when translated material suggests that this concept has been now refuted, it can leave people from those communities baffled. This addition of a new concept which they were not aware of along with inappropriate terms can influence the family's attitudes and understanding of the condition.

Some people have also mentioned that what would be termed as autism in the UK would not be considered as abnormal in their country of origin. This could be because of the degree of severity, or the level of awareness about the condition in the community. It could also be that some cultures have a broader concept of normality or have different expectations around social communication skills and expected levels of self-independence. For example, not giving eye contact may not be considered as a difficulty in communities where giving eye contact to an adult is considered impolite. There is a possibility that understanding and beliefs about autism vary in different cultures depending on what is considered as normal development, and how different behaviours are perceived (Corbett & Perepa, 2007). These differences could also be based on different expectations based on the gender of the child (Perepa, 2008). It is possible that when professionals come across such parents they may think that the family is in denial rather than understanding that the social construct of autism could be different within that community. However, these differences could also mean that when a young person or an adult from certain communities seeks a diagnosis of autism spectrum later in life, they may find it more difficult to explain the condition to their family and friends and may need additional support in this process.

In some cultures disability is believed to be the result of sin or a punishment from God, which has to be borne so that the individual can learn their lesson (Gabel, 2004). Some other families perceive autism as

being possessed by an evil spirit or as witchcraft. In such cultures, the level of support from the wider community to the individual on the autism spectrum or their family members could be minimal. Further, it may also impact siblings' lives such as their marriage prospects. Conversely, some other communities consider it as a gift from God and even provide a higher status to individuals on the spectrum (Shaked & Bilu, 2006). It is possible that in these communities families may resist any intervention as it hinders God's wish. However, it should be remembered that not every individual from a different culture will attribute autism to religious causes and they may and do have similar ideas and myths about causation as the wider community. Families have reported that they consider autism to have been caused because of genetic links, MMR vaccines, difficulties during pregnancy, food intolerance and environmental factors (Perepa, 2008). Personal theories about the causation of the condition influence whether the individual and their family members embrace the label or not. It can also influence how they seek services and support from others, when required.

Having a different understanding could mean that families try other avenues before approaching health professionals for a diagnosis or strategies for intervention. Dobson and Upadhyaya (2002), in their study of beliefs within the South Asian community in the UK, found that members from some of these communities thought that autism can be 'cured' by socialisation and having frequent social contact. Jegatheesan *et al* (2010) suggest that some families may seek the help of a religious healer, or try complementary medicines and home remedies, often because elders in the family have suggested them. The author has also known families who think that their child will outgrow the problem. Lack of knowledge about autism before their child was diagnosed has been reported by more parents from minority ethnic communities than white British parents (Perepa, 2008); because of this, parents and family members could be unaware of the symptoms and may not seek help early enough. Dobson and Upadhyaya (2002) identify this as the cause of limited take up of services among the British South Asian communities. In some minority ethnic communities, disability could be considered as a private matter not to be discussed with others (Jegatheesan *et al*, 2010). In their research, Jegathyeesan *et al* (2010) have also found that such families found accessing support groups difficult for the same reason. These various reasons for delaying seeking help could deny the possibility of early intervention services as the child will no longer meet the age criteria for the service. Some of these issues highlight the importance of raising awareness about the autism spectrum within different cultural groups. Even

so, it is necessary that this awareness exercise is balanced with providing appropriate services for the individuals and their family members to reduce the likelihood of unmet needs (Perepa, 2007).

Even after getting the diagnosis, the way a family reacts to the label of autism could be different and will not always be negative. For example, in their study of mothers' perceptions, Bishop *et al* (2007) have found that African-American mothers felt less negative about having a child on the autism spectrum compared to Caucasian mothers. Although there might be some cultural similarities because of their level of knowledge of autism and how a disability is perceived within their community, religion and personal characteristics could also influence this. These various factors seem to impact whether a family discloses the diagnosis to their extended family and friends or not (Perepa, 2008; Jegatheesan *et al*, 2010). Not sharing the diagnosis with these people can reduce the family's informal sources of support and can lead to a reliance primarily on professional services. It is important that professionals are aware of these situations when working with an individual or their family and where possible help them discuss the implications with their wider family. This is particularly important as extended family members may have an influential role in family matters within certain cultures and be seen as a primary source of support (Perepa, 2008).

Some communities have also mentioned that they are unaware about the role of various professionals and the services that are available (Chamba *et al*, 1999). Limited or no understanding of the dominant language could be one of the reasons for this. Another possibility could be that the service provision is different in various countries and therefore some new immigrants may not be aware of the service systems. It has been noted that a lack of knowledge or misconceptions about services have discouraged families from accessing the services (Perepa, 2002). In fact, Hatton *et al* (1998) state that within the South Asian families living in the UK, the level of take up of services for people with disabilities and their families is directly related to how well they speak English and how long they have been in the country. Therefore, the level of acculturation and social class may also influence the experiences of different people belonging to the same community. This makes it crucial that the service providers create awareness about their services and the procedure for accessing them in a variety of ways, so that different groups within that community are reached, and not just those with good English capabilities.

In some cases, the families from minority ethnic communities may have knowledge about the available services, but choose not to access them

because they feel that the service being provided is not culturally or religiously appropriate for them (Shaked & Bilu, 2006). For example, teaching independence skills is a key area in many school and further education curricula. However, this may not be what the community or the family approves of since interdependency is the preferred way of life in some ethnic groups. Some of these families may also be disinclined to send their family member with autism to a residential home and would prefer more support within their family home. Different communities also seem to value different social and communication skills to teach their children on the autism spectrum. Similarly, some parents may object to their child using an alternative means of communication because of their strong oral traditions or because they see the use of such means as disability indicators (Perepa, 2008).

When using alternative means of communication it is necessary that the individual's home language and its structure is considered, along with the proficiency of English among the family members. For example, if the individual on the autism spectrum is using them in English but their family members are unable to understand English at the same level, it can create a lot of frustration on both sides and perhaps even lead to the exhibition of challenging behaviours. Similarly, differences in word order and the use of verbs and vocabulary between languages can cause confusion. For example, the sentence 'I want to drink water' is expressed as 'I water eat' in Bengali. In such situations, using pictures to communicate in the English word order may not make sense to some members of the family, thereby restricting the possibility of communication.

Different cultures also have different child-rearing practices and different expectations from interventions. For example, in their study, Jegatheesan *et al* (2010) found that some of the mothers found the intervention provided by professionals to be 'too playful' and not directive enough. But instead of explaining their requirements, some families may choose to withdraw from the service out of fear that their beliefs and requirements would either be ignored or ridiculed (Nadirshaw, 1998). Others have indicated that they adapt their language when in contact with professionals from the majority community or from non-religious backgrounds so that they are accepted by them (Shaked & Bilu, 2006). Similarly, some families may not disclose their use of complementary therapies and medicines fearing that medical practitioners would not respect their beliefs (Wong, 2009). It is important, therefore, that practitioners working with individuals from diverse communities engage with the families to find out what their priorities and needs are before devising an intervention plan, developing a curriculum

or providing any other kind of support. This would need to be done in a sensitive manner so that the individual or their family member does not feel they are being judged by the professionals and can genuinely share their thoughts and beliefs.

Cultural norms of the majority community can also influence personal experiences. For example, it has been found that children on the autism spectrum belonging to a minority ethnic community are more likely to be bullied at school and the figures of their exclusions is also high (Corbett & Perepa, 2007). It could be that their being different on two levels – ethnicity and ability – makes peer acceptance more difficult. Similarly, some of the adults with Asperger syndrome from minority ethnic communities known to the author have narrated instances when they were questioned by the police at the various stop and search points set up across London following the 2005 bombing. Due to their heightened anxiety, they found it difficult to communicate and explain themselves in these situations. This brings forth the issue of professional expertise and knowledge. Some practitioners have mentioned that their lack of understanding of cultural norms makes it difficult for them to work with families from minority ethnic communities (Perepa, 2002). It would, therefore, be useful to have cultural awareness as part of autism awareness for professionals so that they understand some of the issues and feel capable to support the individual and their family.

Conclusion

This chapter has raised a range of issues that impact the experiences of people on the autism spectrum belonging to minority ethnic communities and their families. The evidence suggests that people from different cultural backgrounds may have varying opinions regarding the norms expected in social interactions, child development and child-rearing. These differences could influence a diagnosis of autism, perceptions about the condition, the services that the individual and the family seek, and how the professionals and the wider society support the family. However, it is important to remember that individuals' cultural identity is not static and can vary. Hence, perceptions expressed by some members from an ethnic group should not be generalised to the whole community as individual affiliation to a cultural group and personal needs can change at various points of life (Perepa, 2008). Therefore, while some basic understanding about a group's perception can provide an insight into the issues and how to support the individuals belonging to that community, it is vital that understanding of individual circumstances is not ignored and a sensitive and open attitude is

used in every interaction. This wider experience and knowledge of ASC in different cultural contexts will not only increase our understanding, but can also contribute to a fuller definition which acknowledges this diversity.

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Chapter 9:

Autism – a personal perspective

Ros Blackburn

I am autistic. I do not have Asperger syndrome.

Both disorders cause difficulties with social integration, but whereas most people with Asperger syndrome want to be sociable and to be accepted socially by their peers, the majority of those with autism do not want to be sociable, but have to learn to be socially acceptable so as not to upset, interfere with or distress those around them.

Personally, I do not believe in the concept of autistic behaviour. There is nothing that we do that any other human being wouldn't do given the same provocation. It is a well-known phenomenon that people get irritable when they are worried. We are permanently worried because the world around us is a totally baffling, incomprehensible mayhem.

Consider the following scenario: you are walking home late at night when you encounter a group of noisy, drunken youths. Your heart starts to thump. You try to make yourself as unobtrusive as possible. You may even cross over to the other side of the street. You quicken your pace and are highly relieved when you find yourself safely past the youths and even happier when you arrive home to a safe and familiar environment.

But why all the pantomime? Simply because you were frightened!

And why were you frightened? The youths hadn't actually done anything to you. You were frightened because the behaviour of the youths was unpredictable and the situation was out of your control. I am frightened most of the time because to me the outside world is totally incomprehensible, the people in it are totally unpredictable, and I feel out of control.

Along with many other people with autism spectrum disorder (ASD) I often exhibit obsessive, ritualistic and repetitive behaviour and I try to organise things to my own liking. I know that this can challenge the patience of those around me, but I don't do it to be selfish, bossy or difficult. I do it because, by creating an environment of my own making, I feel more in control and I am therefore less frightened (this is in contrast to the situation in obsessive-compulsive disorder (OCD) where the obsession dominates the individual). It is also a common belief that people with ASD exhibit 'challenging' behaviour. The dictionary defines a challenge as 'a task or situation that tests someone's abilities' (Oxford Dictionaries, 2013). So, challenging behaviour is simply behaviour which tests the ability of someone else to cope with it. And it is not the prerogative of a person with ASD; every child at some stage before reaching school age exhibits behaviour which challenges his or her parents.

But with patient parenting *aided by the child's natural inbuilt social awareness*, the unacceptable traits gradually die out. In a child with ASD, however, this natural inbuilt social awareness is absent and he or she has to learn by training alone. Furthermore, the child has to learn for reasons which he or she cannot understand. No wonder, therefore, that this training takes so long and causes so much grief to the trainer and recipient alike. And then, all through life, the person with ASD has to achieve by effort and logic those social niceties which others manage instinctively. No wonder, therefore, that their social responses will always be slower and more stilted than those of a person without ASD.

People with ASD have a reputation for being violent. But this isn't some inbuilt trait that goes with the diagnosis. People with ASD are not violent because they have ASD, they are violent either because they are afraid or because their social limitations prevent them from dealing more equably with an intolerable situation.

Often these situations arise as a result of the altered sensitivity experienced by people with ASD. It is not just that their senses are heightened, but that the sensations have a different impact. Many people do not like a lot of noise, but I cannot stand it – it actually hurts my ears! Even a mildly raised voice will make me put my hands over my ears, which when someone is speaking to me may easily be mistaken for rudeness. I have speech and I have also been rigorously trained by my parents in the art of asking for something without giving offence. So I am now able to say, 'please can you turn the radio down,' or 'please do not speak so loudly' and

explain why I am making the request. But when I was small, often the only way I could stop the awful feeling in my head and ears was to scream. How did this help? I was in charge of the screaming and it was coming from somewhere inside me instead of from outside.

I also hate to be touched, but I would prefer a firm grasp to a light brush of the hand. To me the sensation of a light touch is so disturbing that it blots out everything else and I have to wriggle or rub at the place where the touch has been to try and get rid of the awful feeling. Sometimes I even have to scratch it very hard or pick at it (this is usually construed as self-harming!) to try and replace that awful creepy sensation with a stronger, but self-inflicted feeling that is under my control rather than having been caused by someone else.

When visiting a care home one day, I became aware of a young man sitting in an armchair looking at an Argos catalogue. He was totally absorbed by it. One by one different members of staff came in through the door and yelled at him in that special carers' voice – at least one octave higher than usual and two decibels louder – 'Hello Andy, how you doing? Reading that old magazine again?' And then they would ruffle his hair and go on their way.

Each time Andy would put down the catalogue, rub his ears, straighten his hair and then pick up the catalogue again and go on looking at it.

At the fourth such interruption, Andy lost it! He threw the book at the carer and started trashing the room. Why? In order to put himself in control of the situation in the only way he knew how. He had to stop those voices, the interruptions and that awful feeling in his hair that the ruffling caused.

The carers' day report read 'Challenging behaviour from Andy today'. The carers said, 'We were only trying to be friendly!'

Although people with ASD can be aggressive, they are not intrinsically violent. They do not plan their outbursts or harm anyone intentionally, and their anger is not usually engendered by dislike of a particular person.

I don't 'do' hatred – you can't really work up a good old hatred against someone about whom you feel completely indifferent. I do not hit people because I do not like them. I hit them to get away from them or to get them to back off from me.

Another characteristic often attributed to people with ASD is that of 'non-compliance'. When addressing someone for whom English is not their first language, most people will automatically speak more slowly and will allow time for the person to work out what has been said before expecting a response. When anyone makes a request of me, I have first to analyse each word as though I were translating a foreign language and then, with my muddled understanding of the world around me, try and work out what they actually want me to do.

This, of course, takes time, but so often I am not given that time before the request is repeated – usually in a different form – so that I have to start the process of translation all over again. Then comes the physical prompting: the gentle push or pull. So now I am in real trouble with the sensation business and on it goes...

I know people are busy and often in a hurry, but if they would only give me time to work out what they have said and what they want me to do then I would be far less 'non-compliant'!

As people with ASD go, I am generally regarded as having done pretty well. Apart from being dyslexic, I do not have an intellectual disability, but I am still, nevertheless, severely autistic. I may be intellectually able but functionally I am very disabled. Yet I am earning my own living and am (I hope) reasonably socially acceptable. So how has this been achieved? Much of my success is attributable to the fact that I have speech. But this was only acquired as a result of great persistence on the part of my parents and in spite of great resistance on my part!

Why do so many people with autism not speak? Could it be because speech is a 'social' activity? Think about what happens when a baby utters its first intelligible word. Mother is delighted. She beams, puts her face close to the child, calls him or her a 'clever little thing', and generally makes a fuss of the child. Not what a child with ASD wants at all! So he or she makes a note never to do that again. If a child can get what he or she wants by screaming, grabbing and generally being unpleasant, which keeps everyone at bay, why bother with speech which attracts people's attention?

One of my biggest problems today is finding 'good' carers. What constitutes a 'good' carer obviously varies from case to case, depending on the particular needs of the disabled person. For me, a good carer is one who turns up on time, suitably dressed for the job in hand. It is someone who will not

alter the plans or move the boundaries without good cause and only after carefully explaining to me the reasons why (I am not an unreasonable person, simply an anxious and unconfident one). It is someone who will enable me to achieve rather than do things for me, who will give me clear instructions in simple language, and then give me time to work out what I should be doing. It is someone who will check discreetly that I have my front door key and my travel card before we set off out and that I am wearing clothing suitable for the weather. It is someone who can be unobtrusively watchful and ready to diffuse calmly but firmly any situation that looks like it's getting out of hand. It is someone who will drive me safely and confidently to where I need to go, who will not suddenly leave me without telling me why and who will help me make decisions without imposing his or her own preferences. It is someone who treats 'guidelines' as just that and not as hard and fast rules. Of what use is 'client-led' if I can't make decisions or initiate, or giving me 'choice and control of my life' when 'choice' becomes a nightmare? I do not need someone who gives into my every whim, but who will give me good advice and make wise decisions on my behalf; someone who will help me to give as well as receive.

The best carer I have ever had has been my mother. People sometimes ask me if I love my parents. I have always needed them and used them, but I think that I do now love them. Although, because I have ASD, I do not really know what love is and what I feel for them is born out of trust and respect rather than emotion.

My parents have never been a soft touch and they were both determined that I should fulfill what potential I had. They made me talk. I know the politically correct word is 'encouraged', but that does not do justice to the determination with which they tackled the issue. Screams, tantrums and violence cut no ice with them and I soon learned that polite verbal communication was the best way to get my needs met. They insisted that I learned to obey social conventions and I was not allowed to interfere with or invade the space of other people. My mother patiently but persistently encouraged me to try, and go on trying, new activities, foods, sensations and experiences. She was determined to equip me for life in the real world, which in her view meant having employment and doing things that were useful rather than being wrapped up in special needs cotton wool and being constantly entertained. She didn't accept 'can't', but was always there, doing things with me but not for me. She may have been exasperated but she rarely lost her temper or shouted at me, neither did she ever let up on any issue she considered important. Her maxim

was: 'Never make autism an excuse, but help the person overcome the difficulties caused by it'.

High expectations are essential, but they need to go hand in hand with high levels of support.

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Chapter 10:

Autism – a carer's perspective

Elizabeth Attfield

Introduction

'Happy birthday to you, happy birthday to you…' we sang recently for the 26th birthday of our son, Edward, who has autism spectrum disorder (ASD) and an intellectual disability. As we munched birthday cake, I found myself reflecting on how we ever got to this stage and what I could possibly say as my contribution to this book that would be helpful for families and professionals. For more than a quarter of a century we have been living with the impact of autism on our family life and what follows are largely the musings of one mother who has lived through all those ups and downs. However, I have also attempted to incorporate the perspectives of the very many families of children and adults with a diagnosis of ASD that I have come across over that time span, both as people I have supported as a practitioner in the field of autism and as fellow travellers on the journey towards recognising and meeting the needs of the individuals on the autism spectrum that we know and love.

The analogy of life as a journey is very common, but for me the notion of being on a train that stops at various stations on the way to drop people off or pick them up, while we stay on the train for the whole journey helps me think about the important stages that we have gone through so far. The people we have met along the way, the emotions we have experienced, the lessons we have learned – and the journey is not over yet! I think of our family journey so far in terms of early years, school days, the transition from children's services and, most recently, settling into life where both children are now adults. The impact of living with autism for each member of our family, the difficulties we have had in accessing appropriate services for Edward and getting staff to understand the needs of our whole family are the central themes that emerge. I co-authored a book in 2006 giving a more detailed description of living with autism and am including references

at the end of this chapter for that book and for several others written by parents of individuals with autism that I know and whose writings have helped me personally.

Living with autism

First stop: early years

Edward is the younger of two children and temperamentally very different from his sister, Sophie, but we had no concerns about him as a baby. At his 18-month development check the doctor thought he might be deaf because he was not interested in a simple turn-taking game and was not responding to his name, being much more interested in opening and closing doors and running up and down the corridor. This was to be the start of two-and-a-half years of hospital appointments, clinic visits and a whole range of professionals beating a trail to our door for a series of assessments, interventions and consultations before we finally got a diagnosis of classic autism and severe intellectual disability (SID) for him when he was four years old.

We were so relieved to get the diagnosis because we (naïvely) thought everything would slot into place from then on, but getting the Statement of Special Educational Need (statutory assessment) took 18 months and was very stressful. Our local authority was loath to put the word 'autism' on the legal document, knowing there was no autism-specific provision they could offer us, but we persisted until we got our way. We were luckier than many other families in meeting the eligibility criteria for Easter and summer playschemes, respite care and babysitting organised by social services, but we found it very difficult to find the information we needed when we needed it and everything seemed a huge battle.

Life was hard in many ways in those first few years. I felt like an artiste on an old-fashioned variety show, trying to keep a series of plates spinning on sticks and not letting any of them fall to the ground and smash, while being watched by an audience (the general public) that has no idea of how hard it is to spin those plates. Coping with all the ordinary chores of running a household, taking part in family outings and events, maintaining friendships and close relationships and making sure our daughter's needs were met, as well as managing our son's behaviour, keeping all those

appointments and trying to come to terms with the emotional aspect of the dawning realisation that the child you have is not the child you thought you had – all within the 'goldfish bowl' of the local community – brought us to physical, mental and emotional exhaustion and there was no light at the end of the tunnel.

At three years old, Edward was a 'tornado toddler', rarely sleeping more than four hours a night, on the go the whole time he was awake, ransacking the house and leaving a trail of havoc behind him. He existed in an invisible 'autism bubble', very happy in his own world and seemingly oblivious to the other people in it. It was upsetting that he did not want to interact or communicate with mum, dad or sister, that his play was so stereotyped and ritualistic and his behaviour so bizarre (constantly rocking, clapping and flicking his fingers before his eyes) that he drew unwelcome attention wherever we went. We became increasingly isolated as a family, unable to cope with being stared at and the comments of well-meaning but ignorant people. Like many other families in the same circumstances, we retreated within our own four walls, to keep society at bay because of the lack of understanding and tolerance we encountered.

Second stop: school days

There were some really good professionals who supported us in getting Edward's needs acknowledged and met, but it was still hugely stressful finding the right school for him. Initially, this was an SID school, local authority maintained, and he attended this school from the age of four to 14. A lot of work was done helping him learn self-help skills, introducing him to a pictorial exchange communication system (PECS) when he was clearly not learning speech or signing, teaching him coping strategies for being among people and helping him enjoy a range of activities. We found he was really good at music, sorting and matching colours, numbers and shapes and at gross motor activities like running, jumping and climbing. By introducing music therapy, trampolining, horse-riding and swimming into his life we were able to build on his enjoyment and his strengths to help him (and us) have a more fulfilling, less frustrating life. During these years, we forged our identity as a family living with autism, developed our confidence in managing Edward's behaviour with the support of key professionals in education, health and social care, founded a parent support group and discovered the mutual benefit of doing things alongside other families with similar needs and experiences, including very successful day trips to Legoland Windsor, Chester Zoo and Rhyl, as well

as weekend breaks to Torquay, Blackpool and Disneyland Paris. As our understanding of Edward grew, we were better able to take him on holiday and try to be a 'normal family'.

From ages 11 to 14 we had a tremendously traumatic time in all our lives when the school he had attended successfully for so many years was no longer meeting his needs as a teenager with autism, in a class of young people whose needs were very different. His behaviour deteriorated, as did his mental health; sleeping, eating and toileting patterns went out the window – the 'tornado toddler' had returned with a vengeance as a 'tornado teenager' and life was tough for the whole family. There followed an 18-month battle before we finally succeeded in getting him into an independent, residential special school for young people with severe and complex learning needs just a few miles up the road from where we live. The battle took its toll on my mental health and his dad's, but it was worth it, because now we could look forward to spending 'quality time' with him every weekend and holiday, knowing he was having his needs met during the week while we were taking a break from caring for him. It gave his dad and me an opportunity to have a social life, focus on our own relationship and on our daughter's needs. Edward got used to living away from home and I gradually learned to let go of my 'baby'.

Third stop: transition

After five happy years, we faced the biggest test yet – the move from children's to adult services. Transition planning is so important for people with ASD and their families, but we found it very difficult to impress any sense of urgency on our local intellectual disability team. Finding a suitable placement for someone with ASD that has a vacancy and then getting the funding in place before you lose the place is very stressful – and so it proved. Along the way we also discovered that as parents of someone over 18 you get sidelined and it is difficult to stay in the loop so that your views are heard and taken into account. Despite all that, we remained steadfast and finally achieved our aim to get Edward into an autism-specific, residential adult service in Lincolnshire, but for a couple of years it felt like we were edging along a cliff towards a big, black hole!

Fourth stop: adulthood

It is seven years since our train stopped at this station. In reality, it has just slowed down, because things are still changing all the time. However,

we have been travelling with a relatively stable senior staff team for a long time now and have a good working relationship with them. They understand our son and know where we are coming from in wanting to maintain strong ties with him and have a say in his life. They know our family philosophy about wanting him to have a life, not just an existence, and how important it is for us to feel we are all working together towards that aim. Who knows what the final destination will look like?

Conclusion

So what have we learned on this epic journey? These are the key messages I want people to take away:

- The importance of partnership approaches. Legislation and policy may help or hinder; there will always be a lack of human and financial resources; knowledge and skills may vary widely, but attitude is more important than expertise and by working together in a person-centred way we are more likely to succeed in achieving our aims. Building relationships is key.
- The immense benefits of support groups. Parents are the best support for other parents because they know how they feel and what they need. The same is true of siblings, whose specific needs must be acknowledged and met. Speaking to someone who is ahead of you in the game can be hugely reassuring; there is safety in numbers when you want to do something social and battling together is more effective than battling alone.
- The acknowledgement that we are all only human. Nobody gets it right all the time; nothing is perfect, but staff are usually doing their best. Families need to ask for help; professionals need to listen.
- The recognition that learning never stops. People with autism can fulfil their dreams and achieve their potential, but they need our help and support. We need to get it right and we must never give up.
- The knowledge and understanding that having ASD is a different way of seeing the world. Its impact on individuals and on families is immense, but when services are appropriate and accessible and the needs of the whole family are taken into account, the challenge of seeing the world differently can be very rewarding.

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Chapter 11:

Women with autism spectrum conditions

Jane McCarthy

Introduction

This chapter provides a summary of the literature to date on women with autism spectrum conditions (ASC). It highlights any differences that have been found between women and men with ASC including some of the theories that attempt to explain the difference in prevalence of ASC between women and men. In addition, it looks at differences in presentation and co-morbid health conditions such as mental illness for women with ASC.

Background

There is very little research or studies specifically reporting on the needs of women with autism spectrum disorders (ASD). This compares with increasing research that now looks at the needs of women with intellectual disabilities. Studies of women with intellectual disability have mainly focused on physical health needs, vulnerability to abuse and their roles as parents (McCarthy, 2010). The focus in the studies to date on women with ASC has been around prevalence, presentation and exploring the theories to explain the difference in rates of ASC between men and women.

It has been well recognised for some time that there is a gender difference in the prevalence of ASD. Boys are much more likely to be diagnosed with ASD than girls, with boys three to four times more likely to be affected (Fombonne, 2003). A recent survey of adults in England found that 1.8% of males surveyed had ASC compared to 0.2% of females (Brugha, 2009). Therefore, in studies of children and adults there is a clear difference in the prevalence of ASC across the genders.

Why this difference in prevalence?

A number of explanations for this difference in prevalence are put forward in the literature including genetic or biological factors such as influences of hormones. One theory suggests that the female brain is predominantly hard-wired for empathy and that the male brain is predominantly hard-wired for understanding and building (Baron-Cohen, 2002). This is known as the emphasising–systemising theory. Systemising is the drive to analyse a system eg. a computer or a musical instrument and explore how things work. This is also called the 'male brain' because more males than females show this type of brain. The emphasising–systemising theory may help to explain whether ASC is an extreme form of the male brain with normal or even exaggerated systemising. In addition, those with ASC – according to this theory – may have impairments in emphasising, so intuitively lack the ability to respond to the emotional thoughts of others. This is one possible explanation for more men than women having ASC, but there are a number of other theories.

The androgen theory proposes that ASC is in part due to elevated foetal testosterone levels which are linked with a number of autistic traits. Lower levels of testosterone are shown to relate to social development and empathy. Interestingly, women with ASC report increased rates of testosterone-related medical conditions such as hirsutism, polycystic ovary syndrome, irregular menstrual cycle and acne (Ingudomnukul *et al*, 2007). The capacity of sex steroids to act early in development to alter brain structure and, subsequently, components of the adult brain is not fully understood. However, it is not testosterone but oestrogen which masculinises brain structure. In conditions such as schizophrenia, later onset in women is in part explained by the female sex hormone oestradiol being a protective factor. Therefore, the biological associates of ASC in women remain largely unknown, but it is well recognised that there are gender differences in the development of the brain before and after birth. However, studies of women's brains with ASC suggest that similar regions of the brain are affected as in men with ASC (Craig *et al*, 2007).

ASC is linked to a number of genetic conditions such as Fragile X and Rett's syndrome. These conditions are linked to the X chromosome. Rett's syndrome is a mutation of a specific gene affecting girls with an incidence of one new case in 8,500 female births per year. A genetic explanation has therefore been put forward with Skuse (2000) suggesting that genes for autism are located on the X-chromosome. Girls inherit the X-chromosome from both

parents and boys inherit one from their mothers. The hypothesis put forward by Skuse is that the extra X-chromosome 'protects' girls from developing autism. In general, boys are at a much greater risk not just for ASC but also for a number of other developmental conditions affecting the brain, such as attention deficit hyperactivity disorder (ADHD) and intellectual disability.

The presentation may also differ between women and men, so the recognition and diagnosis of ASC may result in a lower number of women with ASC being identified. Girls and women with ASC may learn how to act in social setups more than boys as part of social expectations of girls to mix and interact more. Girls are more able to observe and copy the social actions of other children enabling them to mask their symptoms of ASC (Attwood, 1997). Women with ASC are reported to have better superficial social skills and language (Gillberg & Coleman, 2000). It may be that for biological or genetic reasons women with ASC, like other women, have the ability or instinct to develop social skills that can compensate to some extent for any disadvantage in their social development.

Girls and women with ASC may present in a number of different ways as described by Gould and Ashton-Smith (2011). They describe the interests of girls with ASC being similar to other girls such as liking animals, horses and dolls, and therefore not being seen as unusual. However, it is the quality and intensity of their interests that differentiate them from other girls. Many are described to have what would be recognised as a circumscribed interest for soap operas and celebrities.

Presentation of mental health and behaviour problems

The majority of studies of psychiatric and behavioural symptoms in children with ASC do not show significant differences between boys and girls (Worley & Matson, 2011). One study reported that boys show more routines, rituals and repetitive behaviours whereas girls as toddlers show greater anxiety and sleep problems (Hartley & Sikora, 2009). However, most studies show little difference in the frequency of behaviour problems such as self-injurious, aggressive or destructive behaviours (Murphy *et al*, 2009).

Problem behaviours have been shown to be equally likely among adult males and females with ASD and intellectual disability (McCarthy, 2010). A study of mental illness found differences between males and females

with ASC (Tsakanikos *et al*, 2010). Personality disorder and schizophrenia were more common among males whereas dementia was more common among females. Differences in clinical management were also found, with males who have ASC more likely to be prescribed a combination of medication, maybe indicating a more severe form of mental illness or their increased risk of schizophrenia. The presentation of personality disorder is still a new area of research in adults with ASC such as the overlap with psychopathy usually described in men. It may be that women with ASC are at more of a risk for borderline personality disorder, which is more frequently diagnosed in females in the wider population.

The presentation of ASC in women

Females may face a number of barriers in diagnosis. They may experience delays in receiving a diagnosis as ASC is less thought of as a possibility in girls compared with boys. Most studies indicate that there is little difference in the presentation of autistic symptoms between boys and girls (Mayes & Calhoun, 2011).

There is still considerable work to be undertaken to tease out gender differences in presentation, severity of impairment related to autistic symptoms and adaptive skills (Rivet & Matson, 2011). Differences in cognitive ability have been found with females who have ASC having lower intellectual functioning than males, with the highest male to female ratio being highest in those without intellectual disability. The gender ratio is 5.5 to one in the average intellectual functioning range compared to a gender ratio of two males to one female in those with severe to moderate intellectual disability (Fombonne, 2003).

For women with ASC, achievement in adult life may be more measured by success at work rather that social success in developing adult relationships. Temple Grandin is a woman with ASC who has been very successful and has written about her experiences (Grandin, 1995). She describes her experience of social contacts through work.

'I know that things are missing in my life, but I have an exciting career that occupies my every waking hour. Keeping myself busy keeps my mind off what I may be missing. Sometimes parents and professionals worry too much about the social life of an adult with autism. I make social contact via my work. If a person develops her talents she will have contacts with people who share her interests' (Grandin, 1995, p.139).

Women with ASC may also present as vulnerable and at risk of exploitation due to their lack of social understanding of intimate relationships. There should be a focus in preparing adolescent females with ASC to understand that personal relationships are about mutual sharing and respect. There is still very little written about women with ASD in regards to these risks. More able women with ASC may have difficulties at work and need specific support. In a video on the SCIE website, a professor at Brighton University describes her experiences at work, particularly around learning the rules of professional communication (see http://www.scie.org.uk/socialcaretv/video-player.asp?guid=D07D967E-8A42-4E6D-A65A-27E3EDF72B0A).

The following case study of a woman with ASC and a mild intellectual disability highlights the issues of vulnerability for women with ASC and the need to diagnose women's ASC earlier to ensure appropriate support through the transition years.

Case study of a young woman with ASC

Zoe is a 21-year-old woman who was admitted to a treatment and assessment unit for people with intellectual disabilities following her arrest by police, having been charged with harassment and wounding.

Zoe was her parents' first child and was taken into care at the age of six after her school alerted the local authority that they felt she was being neglected due to her poor nutritional status and immaturity of speech. Both parents were believed to have mild intellectual difficulties. Zoe then moved through a succession of foster placements. During her time at primary school there were no particular behavioural problems noted, but her teachers commented that she was a very quiet and shy girl, who always seemed to be on the periphery of the other children. She was noted to be behind her classmates academically and received a statement of educational need shortly before transferring to secondary education. Her fullscale IQ was estimated to be 60.

Not long after she started secondary school, Zoe began to present with some behavioural challenges. Her foster carers at this time reported that she had become highly selective about what she would and wouldn't wear and who she would allow to help her style her hair each day. She failed to make any friends at her new school and was spending increasing amounts of time poring over fashion magazines. She struggled to maintain good

Case study of a young woman with ASC (continued)

person hygiene particularly around the time of her period and was beginning to become the subject of bullying. This, coupled with her falling increasingly behind in her schoolwork, resulted in her being transferred to a school for children with mild intellectual disabilities. Zoe seemed to settle in there better and was noted to strike up a friendship with a girl who shared her interests in fashion and make up. Her difficulties were not so apparent in this environment and she remained at the school until she was 19.

In her last year of school she had had a number of 'boyfriends'. These were mainly superficial relationships with peers who were largely unaware of her interest in them. She then developed a crush on a boy who did not reciprocate her feelings. He complained that she was texting him numerous times per day. When he did not reply she would confront him during break times and on one occasion went to his home address. The situation was resolved when his family moved to a different area.

After leaving school, Zoe was placed in residential accommodation run by a local independent provider. She also enrolled on a bridging course at the local college. Soon after moving into the new accommodation, Zoe entered into several simultaneous relationships with young men at college and in the home. After the two young men at the home became aware that she was dating them both, they had a fight and staff felt it would be better for Zoe to move into an all-female home with the same provider, which she did.

Despite the move, the relationship problems continued and Zoe was found to be wandering the streets at night meeting unsuitable men and bringing them back to her room. Staff were worried that she was not able to consent to such relationships and felt she was being exploited as she was increasingly short of money. She then met a young man, Kyle, at the college and embarked on what seemed to be a more equitable relationship. After five months Kyle decided he no longer wanted to be in a relationship and attempted to withdraw. Zoe reacted to this in a catastrophic fashion and then continued to attempt to make contact with him by telephone calls, texts and visits to his family home. His parents were alarmed by the situation and, after she was found to have spent a night outside of their house, they contacted the police. She was charged with harassment and bailed to her residential home with the condition that she did not attempt to contact Kyle.

This contact with the criminal justice system did not alter her behaviour and Zoe continued to bombard Kyle with texts and calls. Two days after her arrest she confronted Kyle while at college. When he repeated that he did not want anything further to do with her, she pulled a kitchen knife from her bag and stabbed him several times in the abdomen.

Case study of a young woman with ASC (continued)

Zoe was arrested and taken to the police station. The on-call psychiatrist was called and she was placed on Section 2 of the Mental Health Act and admitted to the local intellectual disability treatment and assessment unit for further assessment. Following her admission, Zoe was noted to isolate herself from her peers. She was rather dishevelled in appearance and her personal hygiene was poor. However, when staff attempted to get her to change her clothes she was highly resistive and would only consent to wearing the one set of clothes she had been admitted in. She quickly became obsessed with a male nurse and made sexually inappropriate comments in his presence.

It became clear that Zoe struggled to understand social situations correctly and often misinterpreted other people's (usually males') intentions. Her verbal skills were reasonably good but she tended to repetitively ask questions. She did not participate in most of the activities offered to her on the ward, but preferred to spend hours at a time reading magazines aimed at teenage girls. After the clinical team had acquired some of her older social service and medical records, it was clear that she had some degree of speech delay and a number of behavioural difficulties in her preschool years, which her parents had put down to her 'always liking things to be the same'. The clinical team felt that the there was sufficient information in the records that, coupled with their own observations, a confident diagnosis of ASC could be made.

Studies indicate that pre-menstrual symptoms appear to be higher in women with ASC. A recent study found that in a group of young women with dysmenorrhoea and pre-menstrual symptoms there was a less than anticipated impact on the home environment and attendance at school (Hamilton *et al*, 2011). However, for a number of women there was a worsening of autistic behaviour such as repetitive behaviours before each menstrual cycle.

A case example reported was of a woman in her early 30s with severe intellectual disabilities who lived with her parents until her father died, but had recently moved into a supported care home. She had limited communication skills consisting of single words or gestures. She showed a number of challenging behaviours, including biting herself and a ritual of hitting her face at meal times. Her mood was cyclical in nature so she was prescribed a mood stabilising drug. However, on monitoring her behaviour using a menstrual chart, deterioration in her challenging behaviour 24 hours before menstruation was identified. She was diagnosed to have pre-menstrual syndrome and prescribed mefenamic acid with good effect.

We need to create environments that meet the specific needs of women with ASC and that have taken into account their gender. Carers need to recognise that women with ASC share many similarities to other women and will have similar wishes around personal grooming such as hair and nail care. Women with ASC will also have issues around their well-being such as pre-menstrual symptoms as illustrated with the case example.

Conclusion

There seems to be little evidence of any significant difference in the presentation of ASC between boys and girls, men and women. The main difference is that ASC is less common in women than men, particularly in those who are more able. This difference may be explained by biological and genetic factors as discussed in this chapter. However, we also need to recognise that women are less likely to receive a diagnosis particularly in those who are more able. Women with ASC, like women in the wider population, experience different mental health problems than men. Future advances in science may unravel why men are at a greater risk of having an ASC, which may be linked to different developments of the brain and interplay with male hormones such as androgens.

For the present time we need to ensure a greater improvement in the recognition and diagnosis in women with ASC to identify their specific needs and so hopefully improve their outcomes in adult life. In addition, we need to appreciate that women with ASC will have health and personal needs that they share with other women, but we also need to appreciate that they will have needs unique to them as a woman with ASC.

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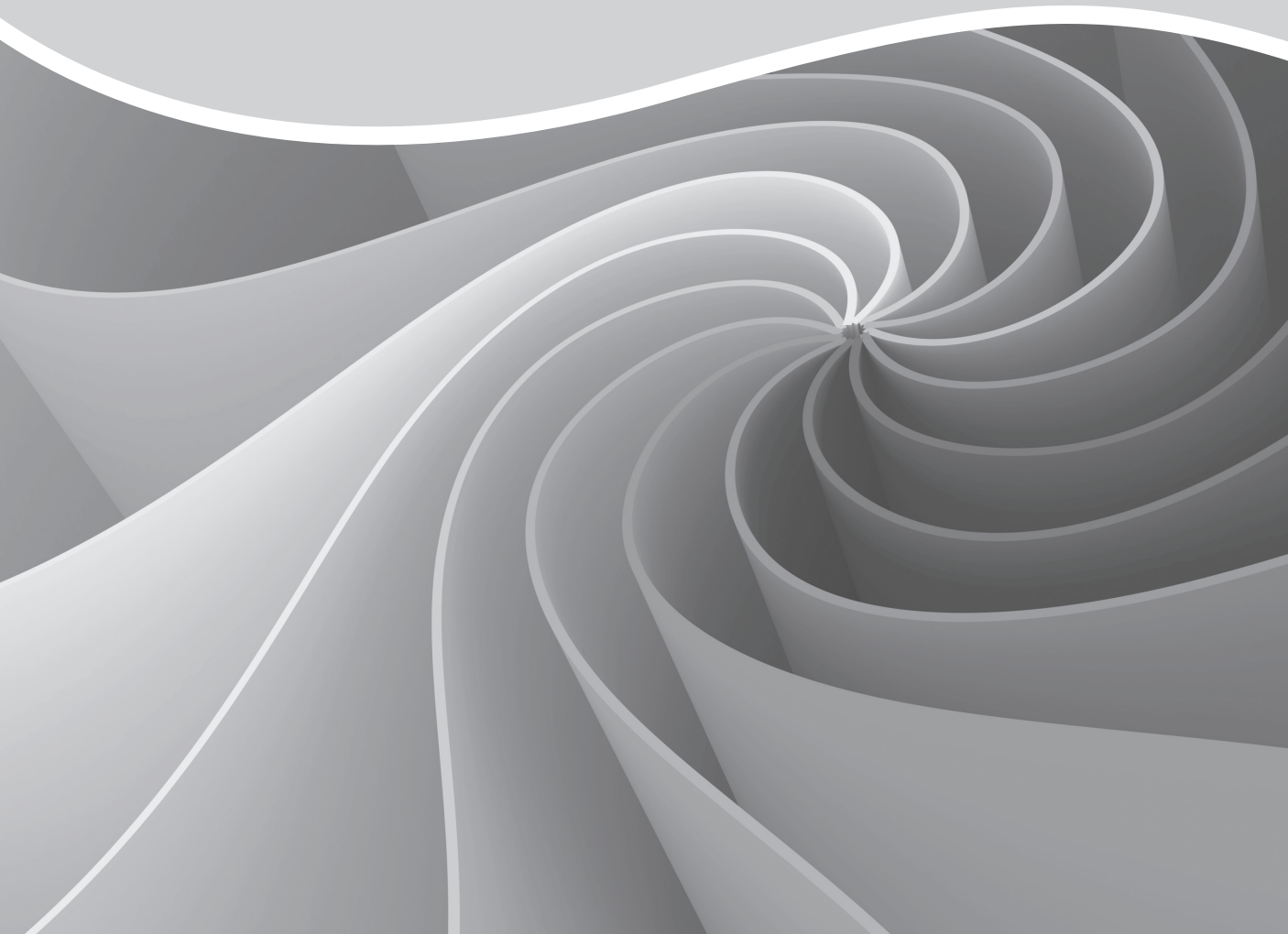
Part 4:

Communication and teaching new skills



Chapter 12:

Communication and interviewing

Jill Bradshaw

Introduction

Difficulties with communication are always present in people with autism spectrum conditions (ASC), and these communication difficulties are one of the ways in which ASC are diagnosed (Bogdashina, 2005). This chapter will describe some of these communication difficulties and will explore possible intervention strategies, illustrated through the use of case studies. This chapter will also present some of the issues around interviewing people with ASC.

Background

What is communication?

Communication is not simply a matter of sending a message into the brain of another person via a code (eg. using spoken words). It is a dynamic process, where meanings are socially constructed and inferred between the people who are involved (Grove *et al*, 1999).

The speaker, the setting, the conversation partner and the context of that particular conversation influence meanings. Each participant will contribute to a message exchange, both as speaker and listener. Rather than being in a passive role, the listener actively contributes to the communication exchange, for example, by relating the topic matter to his or her own understandings of what is being communicated. Each communication exchange can be processed and understood on many different levels. For example, while you

are reading this, you will be relating the information to what you know about communication and how communication works. You will each be thinking something slightly different. You will probably interpret this differently again if you come back to it after reading the rest of the chapter.

Communication and autisic spectrum conditions

The range of communication skills and difficulties experienced by people with ASC is very wide. You may have met people with ASC who are not able to use any speech to communicate. It is thought that around 20% of people with ASC are non-verbal and do not use spoken words to communicate (Lord & Bailey, 2002). Other people with ASC will have large vocabularies of spoken words but will still have difficulties in using the skills that they have to interact with other people. For example, Donna Williams and Temple Grandin, among others, have written extensively about their experiences of living with ASC. They clearly have some very good communication skills but have also written about how difficult they have found both understanding and using communication.

Donna Williams wrote about her experiences of communication:

'I couldn't understand the meaning or significance of what was expected of me because other people's words, intonation, facial expression, body language and touch had no consistent meaning and, therefore, little or no significance.' (Williams, 1996, p2)

Imagine how difficult communicating with someone would be if you had a similar experience. It would be very difficult to work out what people wanted you to do or why things were happening and could lead to a very confused understanding of the world.

The common communication difficulties experienced by people with ASC will be explored in the remainder of this chapter. Difficulties will be illustrated using case studies and explained in relation to research with people who have ASC. Possible intervention approaches will then be suggested.

Main focus and case studies

Difficulties with joint attention

Case study: Jahanara

Jahanara is a young woman with severe intellectual disabilities and ASC. She has recently left school and has moved into a supported living service where she lives with one other person, who also has a diagnosis of ASC. Her family live nearby and she sees them regularly. The staff in the supported living service are having difficulties in supporting Jahanara to become involved in activities. They are not sure how to approach Jahanara and say that she doesn't seem aware of their many attempts to communicate. They think she can hear them but she doesn't seem to respond when they talk to her.

Case study: Fraser

Fraser is eight years old. He was born at 27 weeks and was diagnosed with ASC at the age of three. He attends a mainstream primary school with some additional support. When Fraser was very young, he was generally unresponsive to the communication of other people. This led people to think that he might have hearing loss, though investigations showed this not to be the case.

Parents of children with ASC often report that they find it difficult to interact with their child. The person with ASC can appear to be indifferent to attempts to communicate, to not hear communication or to fail to respond to the communication of other people. Why might that be the case?

The child or adult may find it difficult to attend to an activity or an aspect of an event, object, or to a person. Joint attention is a key skill. It requires the person to be able to divide their attention between at least two things, at the same time. For example, being able to attend to both an activity (or object or event) and to the person with whom the event is being shared. This ability to establish and maintain joint attention is the most common attentional problem in people with ASC (Bogdashina, 2005). This creates a number of difficulties in both language and social development. For a

person with ASC, it cannot be assumed that they will share the focus of attention of the communication partner, even when the person with ASC seems to be looking in the required direction. People with ASC may only be able to focus on either the person or the activity or event.

In either case, there are barriers to learning about communication (and other people). Even if his or her focus is on the person speaking, then they may hear the words spoken but have no clues about what these words or phrases are directed towards (ie. the purpose of this communication). The words that are spoken remain unconnected with the activity. Alternatively, they may be attending to the object or activity and not the person speaking, in which case they may not be able to attend to (or even hear) any words spoken about this object or activity.

'My lack of body-to-environmental awareness probably explains why I seemed to ignore my mother calling me into the house for lunch. I never heard her. She would have to actually touch me to make me aware of her presence.' (Shore, 2003, p.87)

Thinking back to the case study, what do Jahanara's staff team need to do to help her to attend to their communicative attempts? They probably need to have a consistent strategy in use to gain her attention. It will be easier for her to understand communication if people always approach her in the same way. The following strategy may be useful.

Jahanara has difficulties in switching her attention between objects, activities and people. Before attempting to communicate, reduce as many distractions in the environment as possible. Reduce the background noise and, if possible, ask other people to either leave the room or stay quiet.

- To initiate communication with Jahanara, position yourself in her line of vision.
- Say her name at the start of the interaction, touching her gently on the back of her hand as you say her name.
- Give her clear information about the activity, backing up what you have said with a visual cue (eg. using the duster as a clue that she is going to be dusting). You may need to give Jahanara time to process what you are communicating.
- If she does not respond, wait a few seconds before repeating the communication using the same strategy.

Difficulties using communication for a variety of purposes/social communication

Difficulties in joint attention also have an influence on the purposes or reasons why people with ASC communicate (Wetherby, 2006). Children with ASC have particular difficulties in initiating communication for the purposes of joint attention. They are more likely to communicate for the purposes of requesting or protesting, rather than to comment or direct another person's attention towards something.

Even when communication skills are relatively good, social communication difficulties are likely to persist. For example, writing about his life experience on the National Autistic Society (NAS) website, Simon describes his lack of understanding of how to make small talk.

'*… I'd always found it difficult to make small talk until I read that the aim of such conversations is to merely pass the time, and that it's OK to drift from topic to topic without reaching specific conclusions. If only I had known it was that simple!*' (NAS, 2012a).

Difficulties using and understanding non-linguistic communication

Case study: Rob

Rob is six years old. He has severe intellectual disabilities and ASC. Rob is non-verbal. When he wants something, rather than pointing, he will often take an adult by the hand and lead them to what he wants. If staff try to use pointing with him eg. to show him where something is, Rob doesn't seem able to follow the direction of the point. Why is Rob unable to understand pointing?

Case study: Jim

Jim is 50 and has moderate intellectual disabilities and ASC. He is able to communicate verbally. He tends to use a flat tone when he talks, which can make it difficult to listen to him. His rate of speech is also unusual. He tends to sound out each of the words at a fairly slow rate, even when he is excited about something that he is telling you about.

People with ASC may have difficulties in understanding and using facial expression, tone of voice, rate and fluency of speech, and gesture. For example, their facial expression may not reflect how they are feeling (eg. smiling while screaming and clearly upset). They may also not be able to 'read' other people's facial expressions and body language. For people without ASC, these are important signals, which give us a lot of additional information about the words that are being used. We use this information, for example, to judge whether or not the person is interested in what we are saying, whether we are saying too much or too little, whether they understand the information we are giving them and whether they are confused.

Children who have communication difficulties but do not have ASC will often compensate for their communication difficulties by using additional means of communication, such as gestures eg. if they are unable to use the word for drink, they may well point and vocalise. This is typically not the case for people with ASC (Wetherby, 2006). Children with ASC tend to use contact gestures (eg. leading, pulling or direct manipulation) rather than conventional gestures (eg. waving, pointing or showing) or symbolic gestures (eg. nodding the head) (Loveland & Landry, 1986). This is because there is a direct link between the contact gesture and the communicative intent, whereas the meaning of conventional and symbolic gestures is less obvious and has to be learnt. Intonation (or pitch) is also often impaired (Tager-Flusberg *et al,* 2005). For example, people may use a very flat intonation pattern and they may appear monotonous.

Grandin (1999) writes:

'I did not know that eye-movements had meaning until I read Mind Blindness by Simon Baron-Cohen. I had no idea that people communicate feelings with their eyes.'

Echolalia

Case study: Amelia

Amelia is 13 years old and has severe intellectual disabilities and ASC. Staff are trying to offer Amelia choices of activities, but they are finding this difficult as Amelia often just repeats back the choice that is being offered.

The child or adult with ASC may repeat words or phrases that they have heard. It is possible to repeat something without having any understanding of what has been said. There might be a number of reasons why children with ASC are echolalic and for some children this is a stage in their language development:

- Repeating a phrase may enable the person with ASC to take part in a conversational exchange. If you are able to repeat back some or all of what the other person has said, that might be one way in which it is possible to take part in an interaction.
- Echoing may also be used as a strategy to give the person additional time to process and respond (Bogdashina, 2005).
- There is also some evidence that people with ASC may use echoed speech to either increase the level of stimulation in the environment or as a strategy to help to block out other stimuli. Children may, for example, echo more when they are feeling particularly anxious.

Perseveration

Case study: Clive

Clive is 42 and has mild intellectual disabilities and ASC. He lives with three other people, all of whom have severe intellectual disabilities. He likes to interact with the staff and can talk constantly. He has great difficulties in ending an interaction and can often be heard carrying on the conversation even after the person he has been talking to has left and is walking away down the street. He has a number of topics that he particularly likes to focus on, including places around where he lives and directions for travel between these places. Staff find it very difficult to encourage Clive to move on once he has started to talk about one of his topics of interest.

People with ASC may also repeatedly focus on phrases or topics. These are often topics of particular interest (Happe, 1991). For example, a child may ask the same question over and over again, even when the answer is known. In such exchanges, the child or adult may expect a particular answer (and may become distressed if this answer is not given) (Bogdashina, 2005).

In describing her repetitive communication, Ros Blackburn (2000) writes:

'Another big reason for doing what I do is to get a reaction from people that I am ready for … This quite often may also be entertaining or it may be to delay or dodge a less pleasant or less predictable issue' (p5).

Perseverating on a particular subject may enable the person with ASC to retain control over the conversation. This can be a strategy that is used to mask difficulties in comprehension; if you set the topic then you have more chance of understanding what people are talking about. Repetitive language, like repetitive behaviours can be very persistent and difficult to change.

So what can the staff do to help? When Clive is having difficulties it may help to:

- remember that Clive may be more likely to perseverate in times of anxiety or when he is having difficulties in understanding
- try and reduce the distractions in the environment and try and find ways around whatever seems to be increasing his anxiety
- make sure that they are simplifying their communication, making things as easy as possible for him
- ask Clive to stop; a visual cue may also be useful (eg. raising their hand to indicate stop)
- remind Clive what the topic of conversation should be or introduce a new topic of conversation; again, having a symbol of the topic area or drawing his attention to the activity may be useful
- move position in the room eg. switching chairs, to see if that is helpful
- as a general strategy, staff should also try and have some consistent ways of starting and ending conversations.

Pronoun reversal

Case study: Simon

Simon is 11 years old. He has severe intellectual disabilities and ASC. Simon will often talk about himself in the third person. For example, he will say 'He did it' when he is talking about something he has done or 'He wants a drink' when he means 'I want a drink'.

Referring to themselves by their own name and difficulties with the application of I/me/you/she/he are common among people with ASC. This is likely to be because these words are not labels which can be consistently applied to a person, but shift according to roles in conversational situations (Bogdashina, 2005).

Donna Williams (1996) wrote:

'Pronouns are, in my experience, the hardest words to connect with experience-able meaning because they are always changing, because they are so relative. In my experience, they require far more connections, monitoring and feedback than in the learning of so many other words' (p160).

Literal understanding

People with ASC often interpret language literally, without looking for the possible meaning behind the communication. Sarcasm, irony, humour and metaphorical language (eg. I nearly jumped out of my skin; I nearly died; it's raining cats and dogs) are often difficult for the person to understand. They may interpret these phrases literally, focusing on meaning rather than intention (Bogdashina, 2005). How many other common phrases can you think of that have a rather different meaning if they are interpreted literally?

Idiosyncratic language

People with ASC may have some idiosyncratic speech; using unusual words for objects or situations. These are words or phrases which are based on unique associations. It is therefore difficult to infer meaning from such remarks because these associations are often not accessible to communication partners.

Comprehension of communication

It is also important to note that though expressive language is often the focus of discussion for people with ASC, receptive language difficulties may also be apparent. Indeed, some research suggests that in young children delays in the comprehension of language may be strongly linked with ASC (Mirrett *et al*, 2004).

For people with ASC who verbally communicate, it is probable that they are able to use more complex language than they are able to understand (Vicker, 2001). This is often because of his or her use of echoed phrases (which they may use but not understand). It may also be the case that the person with ASC is using seemingly appropriate responses (eg. 'I can't remember'). This may mask difficulties in understanding.

Communication and the SPELL framework

The SPELL framework (Beadle-Brown & Mills, 2010) was developed by the National Autistic Society (NAS) as a framework for understanding and responding to the needs of people with ASC. SPELL stands for: Structure, Positive approaches and expectations, Empathy, Low arousal and Links. This approach also focuses on good communication strategies. The SPELL framework can also be applied directly to good communication with people with ASC. For example:

- **Structure:** making communication predictable. Focusing on what is happening now and what will happen next. Providing visual and gestural supports as needed. Visual cues are often particularly useful for people with ASC.
- **Positive approaches and expectations:** giving clear opportunities to take part in successful communication. Being responsive to any indications that the person has not understood or that the person wishes to terminate the conversation. Remember that if the person is repeating back what you have said, it does not necessarily imply that they have understood it.
- **Empathy:** thinking about communication from the point of view of a person with ASC and making necessary adaptations eg. within comprehension skills.

- **Low arousal:** thinking about how you communicate eg. tone of voice, rate, facial expression, gestures etc. and thinking about the environment that you are communicating in.
- **Links:** thinking about all the situations in which person will be communicating and about how you can maximise their skills so that they are able to make and maintain links.

Other general strategies which may be helpful include (Vicker, 2001):

- recognising that expressive skills may exceed comprehension
- saying exactly what you mean and using phrases which do not have to be interpreted.

Interviewing people with ASC

Interviews (particularly for employment) often require the same question format for each interviewee. This strategy is unlikely to make the most of the skills and abilities of someone with ASC. The NAS suggest a number of strategies which could be helpful when interviewing people with ASC. These include:

- Asking closed rather than open questions. People with ASC may find it more difficult to answer open questions such as 'Can you tell me why you want this job?' as there are very many possible answers. Their communication difficulties and difficulties with theory of mind may mean that they are not able to think about what information the interviewers want to know (difficulties thinking about the reason behind the question).
- Asking specific questions which are about what the person has done in the past and avoiding hypothetical or abstract questions. People with ASC will have difficulty imagining and so it is better to ask questions which clearly relate to actual experiences.
- Being aware that the person may well find it difficult to work out how much information to provide in answer to the questions asked. Interviewers may need to tell the person that they have provided sufficient information or to prompt with specific prompts (eg. you have told us about X, now please tell us about Y).

- Making sure that questions are not ambiguous as the person may interpret the questions literally.
- Making allowances for differences in eye contact, facial expressions, body language etc. The person may have difficulty in both reading these signals in others and in using these appropriately.

Work trials may be a more useful way of assessing someone's ability to carry out the job, in some circumstances.

Think about the strengths and skills of someone with ASC that you know. What jobs do you think would enable the person to use these skills? Think about what questions you could ask during an interview. Make sure that these questions are specific, relate to past experiences, are unambiguous and clear.

The NAS (2012b) has some tips for employers on interviewing people with autism and Asperger's synrdrome at: http://www.autism.org.uk/our-services/employment-support/employers/factsheets-for-employers/tips-for-interviewing-people-with-autism-and-asperger-syndrome.aspx (accessed April 2013).

Conclusion

The range of communication difficulties experienced by people with ASC is very wide. It is important that an assessment is carried out of the communication strengths and needs of the person with ASC and the wider communication environment. This should also include how skilled other people are at adapting their communication to the needs of the person with ASC. Successful interventions will enable the person with ASC to maximise the communication skills that they have and enable them to take part in successful communication exchanges.

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Chapter 13:

Teaching skills

Carmen Brock-Southon and Tina Bang-Anderson

Introduction

This chapter discusses the considerations and process when teaching skills to people with autism spectrum conditions (ASC) and explores the main difficulties to learning that are commonly experienced. Language and communication will not be included in detail as this topic is covered in **Chapter 12**. Difficulties are discussed using case study examples along with strategies for intervention. The aim is to equip the reader with techniques to teach individuals basic skills which may result in full or some aspects of independence in the everyday tasks that most of us take for granted.

Background

Individuals with ASC will usually have some or all difficulties related to their cognition in the following areas, dependent upon their functional level. The following are examples of these difficulties.

Executive functioning is a term used to describe cognitions governed by the brain's frontal lobes and includes functions such as multi-tasking; initiating, sequencing and terminating tasks; planning; problem solving; self-regulation, and mental flexibility (Hill, 2004) (definitions are given in **Table 13.1: Examples of executive functioning**).

Table 13.1: Examples of executive functioning

- **Multi-tasking** refers to processing multiple information simultaneously, while coping with distractions.
- **Initiating** is the ability to start the first step of an action.
- **Sequencing** is putting the steps of an action into the correct order to complete the whole action.
- **Termination** is stopping (terminating) an action.
- **Planning** involves the whole sequence of goal directed actions being constantly monitored, reviewed and modified.
- **Problem solving** involves anticipating and responding to difficulties that arise in the individuals' environment.
- **Self-regulation** is controlling (regulating) emotions, desires and responses that govern behaviour and has two major concepts:
  1. The ability to control impulses, an example would be an individual with auditory sensitivity staying in a noisy environment such as a crowded room.
  2. The ability to do something the individual may not want to do, for example making eye contact (Geneva Centre for Autism, 2012).

Other cognitive difficulties that may affect the delivery of teaching include:

- **Theory of mind** is having an understanding of others' mental states. Individuals with ASC have difficulty conceptualising and acknowledging others' thoughts and feelings, which may cause offence or embarrassment (Attwood, 2005) and in the extreme can make the individual vulnerable.
- **Rigid/inflexible thinking** refers to thinking in a rigid one-way manner with difficulty adapting to a change in thinking and having a single approach to a problem.
- **Poor verbal memory** refers to the ability to remember words.

Teaching skills and autism spectrum conditions

According to the Oxford Dictionary (2012a; 2012b), to teach is to '*give information about or instruction in*' and skill is '*the ability to do something*

well'. Teaching skills happens naturally in the majority of families. For individuals with ASC, using interventions such as prompting, visual aids, modelling and positive reinforcement may also be required to help the person develop skills. There are other methods such as grading and chaining for tasks that may take more practice. It is crucial to recognise the good work and strengths of the individual, when focusing upon areas for development. This is in order to motivate the individual and to provide a positive learning environment. Many individuals with ASC have a good understanding of concrete concepts, think in a visual way, are able to recall visual images, and are able to learn by repetition.

Individuals with ASC commonly experience problems in some or all of the following areas: social interaction; self-awareness; impulse control; self-regulation; communication; sensory processing; interacting with their environment and cognitions, all of which are barriers to learning. For example, an individual with Asperger syndrome and an IQ of 130 may be academically able, having a place at university. However, the same individual may be unable to plan and organise their day or attend to daily living tasks such as personal care due to executive functioning difficulties. Prior to teaching any new skill or reinforcing an existing skill, the first step is to engage the person. This may be by directly talking to the individual, showing a visual prompt such as a picture, or by touch. Once engaged, the person can be told or shown what to do. When a task is attempted or completed it is important to give praise as positive reinforcement (Dodd, 2005a). A single teaching method may be used or multiple methods used simultaneously, as will be demonstrated in the case studies.

Individuals with ASC require structure, consistency, repetition, clear communication using simple language, and a positive environment for learning to take place. Whatever teaching methods are employed, they should allow the individual time to process and respond to the information. This will vary according to the individual's level of functioning. If a person does not respond in the way predicted, this does not necessarily mean they have not understood. It is therefore important to try to understand the individual's learning strengths and any barriers to learning to ensure the most suitable method of teaching is selected to suit their specific needs.

Teaching methods

A summary of some of the most common teaching methods used with people who have ASC to develop skills follows.

Visual cues

Visual clues can be in the form of pictures, symbols or written words. The visual prompt is used to inform the individual about what to do regarding a task or in a given situation. The individual may respond better to certain cues and have a preference. Visual cues can be used either on their own or in addition to simple word commands or more complex speech patterns.

Adding structure

Structure allows the individual to know what task they are doing and when they are doing it. Individuals with ASC like sameness. Many people with ASD function well with a stable, consistent routine, which is highly structured. Changes in routine should be kept to a minimum and new changes introduced gradually; there should be no surprises. Visual cues as mentioned above in the form of timetables, pictures or symbols (depending upon the individual's level of understanding) can be helpful when introducing new routines and meeting unfamiliar people.

Verbal prompting

Verbal prompting is the use of a verbal command to indicate what the individual should do in a given task or situation. It is important to keep verbal communication as simple as possible to avoid sensory overload. Avoid using metaphors such as 'broken heart' and use concrete language and explanation to prevent confusion.

Modelling

Modelling involves a physical demonstration of what the individual is expected to do in a given situation. Most children and adults have learned new skills by being shown through modelling the different steps in an activity. This process may also happen in families, such as children copying their parents. When developing skills using modelling, physical demonstration can be accompanied by a verbal prompt, visual cue or symbol; this combined method can be a useful strategy for individuals with a learning disability.

Chaining

Chaining breaks down a whole activity into small steps (a chain) that are taught one step at a time in the correct sequence to make the activity whole again (Schotte, 2010). This is often taught using modelling. Forward chaining is teaching the first step of the process or chain required to complete a task before proceeding to the second step and then the third, until all steps of the activity are complete. Backward chaining starts with teaching the last step first, working through the sequence until the first step is reached. Backward chaining has the advantage that the individual has an instant end result, which can be a positive incentive and motivator. Visual pictures of the sequence are often used and can be helpful, but may be seen as patronising if the individual is more able and does not require visual prompts.

Social Stories

The Social Stories technique involves telling an individual short stories about a social situation. The story is used to demonstrate appropriate social cues, behaviours and responses (Gray, 2012), which the person is encouraged to learn. The stories can be in a visual form of pictures or symbols dependent upon the individual's learning needs and level of functioning.

Comic strip conversations

These are conversations between two or more individuals using drawings to demonstrate a reciprocal conversation. This is a helpful method for individuals who have slow processing and have difficulty following and understanding a to-and-fro conversation (Gray, 1994).

Role play

This involves the individual practising or acting out a scenario in order to change a problem behaviour and understand how to behave in a specific situation. The individual needs to understand the social context of what is being asked of them prior to the role play. This method can be helpful in teaching social skills and can be used to reinforce visual cues where concrete rules are required and to practice Social Stories. An example of role play would be an individual who has problems turn-taking and pushing in front in a queue. The teacher would role-play the person at the front of the queue, with the individual being asked to wait behind the teacher until it is their turn.

Grading

Grading involves making a task easier or more difficult depending on the individual's level of achievement. This method can only be used once the basic skills for the task are part of the individual's normal repertoire, which would be gained using other teaching methods.

Adapting the environment

Environment adaptation involves making permanent or temporary environmental changes to allow optimum learning to take place. This is particularly important for those individuals who experience sensory processing difficulties. An example would be reducing the amount of noise to assist an individual's concentration when teaching a task. A permanent solution may involve the individual using a physical aid such as constantly wearing ear plugs and a more temporary solution would be reducing the noise by using a quieter room while teaching takes place.

It is important to know that many people with ASC have difficulties with sensory processing. How we view or interpret the world is made up of our own mental picture. Sensory perception is the process in which individuals collect, make sense of, and understand information from the environment (Bogdashina, 2003). As well as using the senses of taste (gustatory), touch (tactile), sound (auditory), smell (olfactory) and sight (visual), consideration needs to be given of other factors eg. the awareness of where limbs are in space (proprioception) and balance (vestibular).

There are three stages involved in sensory processing:

1. **Sensations:** the feeling of pain, pleasure, temperature, touch, smell, taste, falling etc.
2. **Interpretation:** the brain is unable to process all the information it receives, therefore it selects what it considers to be important, ignoring the rest of the information. Once processed by the brain, the sensory perceptions are central to a number of cognitions such as imagination, mental associations, experience and memories in order to make sense of the world.
3. **Comprehension:** this is the final stage and is the behaviour that has resulted in response to the sensory information. It includes monitoring, integrating and keeping up with the sensory incoming information all at once. Our senses are used simultaneously and mostly subconsciously. According to Hatch-Rasmussen (1995), sensory integration is the brain's

interpretation of sensory information from the environment. Sensory integrative dysfunction occurs when the brain is unable to construct the information in a purposeful way, resulting in problems with behaviour, development and information processing. People with ASC find multiple processing or multi-tasking (processing several different sensory stimuli at once) difficult and this can lead to sensory overload. A self-regulation strategy could be used in this situation. This is designed to deliberately avoid or reduce the sensory stimuli and includes efforts to make sensory exposure more predictable (Brown & Dunn, 2002). In contrast, some individuals may be under-stimulated. Often when this occurs, the person will actively seek sensory stimuli such as bright colours, noise, touch and smells, or may seek certain stimuli but avoid others. A series of brief case studies now follow that describe scenarios and interventions that a person can be taught to help with a number of issues. The case study (Luke) is designed to illustrate how a person may cope by avoiding situations where sensory perceptions and sensations become aversive and strategies that can be used to try and address the situation.

Case study: Luke

Luke is a 22-year-old man with ASC who is oversensitive to light. Luke was having problems walking outside and ascending or descending stairs. This was because Luke has difficulty noticing his environment due to closing his eyes to avoid light and his dislike of feeling off balance due to motor dyspraxia. He showed sensation avoidance behaviour in that he deliberately avoided parts of the house, stairs and uneven ground where he felt he was at most risk of falling, resulting in him isolating himself in his room.

Interventions that might help Luke

Physical aids

It may be that a number of strategies are required. In this case, Luke benefited from wearing dark glasses to adapt his environment. Reducing the visual sensation of light helped him to concentrate as he found too much light overwhelming. This gave him confidence to use coping cards.

Coping cards

Working with Luke and giving him visual cues of and/or positive statements so that they have specific meaning to him eg. positive mantras

such as 'I can walk alone; I will not fall down the stairs'. Small pocket-sized cards can also be used as a coping strategy, which Luke has been prompted to look at if he becomes anxious.

Verbal prompting

The use of verbal prompts should not be underestimated. To assist Luke, staff helped him avoid distractions and pay attention to his environment, verbally, reminding him 'Keep your eyes open, look straight ahead, not at your feet' and gradually reducing the prompts session by session.

In another example, Joe gets gratification through inappropriate touching of staff, in particular stroking their hair.

Case study: Joe

Joe is a 22-year-old man with ASC. He touches staff inappropriately by patting their shoulders, putting his arm around them and trying to stroke their hair. He particularly likes long blonde hair because of its colour and texture.

Interventions that might assist Joe

Adapt the immediate environment

This can be done by giving access to appropriate tactile stimuli. In this case, Joe was provided with sensory balls of different textures and colours. One ball was pocket-sized and Joe kept it with him at all times. The occupational therapist and Joe made a sensory box containing fabrics of his favorite textures and colours that he would stroke in his room. If Joe then attempted to touch staff he was reminded to squeeze his sensory ball through verbal prompting and distraction.

Difficulties with social awareness and interaction

An individual with ASC will typically have problems in forming relationships with others; reciprocal interaction; communication; imaginative play; copying others and understanding that others have their own thoughts and feelings. Following intensive study, Wing & Gould (1979) concluded that

ASC presents as a continuum, with different presentations that are part of related disorders on a spectrum. This indicates that individuals are affected at varying levels. The depth of problems experienced varies according to the individual's level of functioning; ranging from subtle difficulties to those with intellectual disabilities. Many individuals with ASC have empathy, feel deep emotions, are outgoing and are motivated to socialise. However, they have difficulty recognising, articulating or expressing their emotions as well as understanding and dealing with social situations.

The next case study describes John, who has problems with social awareness.

Case study: John

John is a 22-year-old man with ASC and obsessive-compulsive disorder (OCD). He has a poor understanding of others' mental states and social awareness. Due to his OCD, John will stand ritualising for many minutes, invading an individual's personal space and putting all of his belongings on the floor in busy public places. These behaviours make him vulnerable to assault and theft when out in the community.

Interventions designed to assist John

Modelling

Staff would model how close John could stand to them (one arm's length away) by standing in front of John and extending their arm. To practise this, John had cue cards which were kept in his pocket and contained the following concrete rules:

- keep one arm's length away
- people may steal my belongings
- don't stare; this worries people
- don't stand too close.

Verbal prompting

This was also used when John was too close to others. On these occasions staff would ask him to look at his **cue cards**. If, on occasion, John kept

engaging in the behaviour, staff would advise him of this and ask him to step away. If John was inappropriate in any way, staff would quietly point this out to him at the time, with an example of the behaviour.

Difficulties with language and communication

Individuals with ASC have problems in four main areas of language and communication: understanding language, expressing language, verbal skills and non-verbal skills. The severity of language and communication problems will depend upon the individual's functional level. This can range from having little understanding with little or no verbal language, to having good comprehension of language and conversational skills (Dodd, 2005b). Individuals with good language and comprehension who can speak articulately about their own interests may struggle in unstructured situations and can be disabled in social situations.

The next case study looks at a person with good vocabulary and understanding, but who has difficulty in articulating his needs.

Case study: Philip

Philip is a 24-year-old man with ASC. He has an above average IQ and was at university prior to hospitalisation. He is able to comprehend language and communicate verbally. Philip was having difficulty having his needs met by shop staff in the community due to problems articulating in unfamiliar or unstructured situations. When asked an unexpected question by shop staff, he would flush red with embarrassment, stammer and look helplessly around before rushing away from the situation and leaving the shop staff confused. As a result, Philip began to avoid shops, preferring to do his shopping online.

Interventions to assist Philip

Role play

Philip's occupational therapist (OT) role-played a shop assistant and asked him various questions that he had found difficult to answer along with other possible scenarios with Philip practising his answers. The OT would then give praise and verbal feedback on how to improve on one area at a

time. To put this into practice, going out was structured. A timetable was used so Philip knew when he would be going out and where he was going. He would choose which shops he would go into and have a written plan to follow. His OT devised with him a safe gesture (Philip pretending to scratch his ear) as a secret code for 'Help me, I can't deal with this'. This helped to reduce his anxiety as he knew there would be assistance from his OT or whoever was accompanying him. Knowing he could use the safe gesture allowed Philip to stay in control.

A graded hierarchy of situations was developed with Philip and **repetition** was used in role play so he could become completely comfortable with a scenario before moving onto the next. To monitor anxiety when going out, trips and situations within trips were **graded** in terms of how anxiety-provoking they were. To increase independence, the person supporting Philip would adjust their proximity to him gradually over many weeks moving further away from him.

The final case study looks at helping to teach skills to develop Tony's self-care and reduce dependence.

Case study: Tony
Tony is a 22-year-old with ASC who has an intellectual disability. He is unable to dress himself.

Interventions used to assist Tony

Chaining

Backward chaining was used; staff would dress Tony until the last garment – his jumper. Staff would put the jumper on him and Tony would be shown how to pull it down by modelling. Tony would copy staff pulling the jumper down. The next step was to put his right arm in the jumper, the next step being his left arm and finally his head. This method was used with his other clothes until he could dress himself with visual cues and verbal prompting only.

Visual cues

Tony was given pictures of the chaining sequence; staff pointed to the picture correlating to the step being used in chaining.

Conclusion

Through a variety of case studies, this chapter has explored some of the strategies used to promote learning and for teaching and developing skills for individuals with ASC. People with ASC think, learn, perceive and respond differently from their peers without ASC. It is important to understand and teach to people's strengths with positive reinforcement as there is no specific method that will work for everyone. Usually, teaching and developing skills means that in each case a variety of methods are adopted that are tailored to meet the individual's needs.

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Chapter 14:

Innovative technology-based interventions for people with autism spectrum disorders

Christos Nikopoulos and Elias Tsakanikos

Introduction

During the last decade, there has been a shift in emphasis from language-based instruction to more visual instructional supports as a catalyst for learning in individuals with multiple disabilities and autism spectrum disorder (ASD) (eg. Bondy & Frost, 2001; Quill, 2000). This is due to extensive reports that individuals with ASD demonstrate enhanced performance in comparison to matched controls on simple visual search tasks that require detecting a target set among distracters (eg. Dawson *et al*, 2007; Mottron, 2011; Simmons *et al*, 2009). For instance, individuals with ASD generally perform well on the Wechsler Intelligence Scale for Children (WISC) Block Design test, the embedded figures test, visual search, and copying impossible figures as well as on the Raven's matrices (eg. Fugard *et al*, 2011; Soulieres *et al*, 2009).

Given the visual superiority of people with ASD, it is perhaps not surprising that the majority of current educational programmes for these individuals frequently employ visual supports. Picture prompts, photographic activity schedules, visual schedules, or videos appear to be appropriate and particularly motivating for these individuals (eg. Dawson *et al*, 2000; Kamio & Toichi, 2000; Rao & Gagie, 2006; Shane & Albert, 2008).

Advances in information and communication technology (ICT) have led to a number of innovative applications (Doughty *et al*, 2007), in which many of the above visual supports have been integrated, forming the design of

technology-based interventions for this population. A non-exhaustive list of examples includes the use of the internet, online communities, robotics, assistive and prompting devices, iPods, computer-aided instructions, video modelling, virtual reality, voice output communication devices, computer-training (affect, social cognition, language), telehealth, telemedicine, smart housing, home automation, computer-play and others (eg. Goodwin, 2008; Verdonck *et al*, 2011).

Technology-based interventions have been used to accommodate a wide range of different skills and deficits in individuals with ASD. Recent studies have attributed this to a number of factors.

- Among typically developing individuals, technology-based applications are widely used for leisure and educational purposes, as a result, they are perceived as social interaction interventions.
- Technology-based interventions enable the individual with ASD to participate in a meaningful way in the wider community life by facilitating new communication, socialising, learning, leisure and employment opportunities (Bolte *et al*, 2010).
- Technology-based interventions can serve as efficient and cost-effective tools as they remove, for example, the requirement to create and re-produce paper-based training aids (eg. Nikopoulos & Nikopoulou-Smyrni, 2008).
- It is common for people with ASD to respond to a restricted set of cues within an environment; a phenomenon known as stimulus over-selectivity (eg. Lovaas & Koegel, 1979; Rincover & Ducharme, 1987). Technology-based interventions can be utilised to bring relevant cues closer together, which can help people with ASD to follow respective cues and to discriminate between them. This is important to develop skills in imitative responding (eg. Morgan & Salzberg, 1992).
- Technology-based interventions can efficiently take advantage of the attention skills of individuals with ASD, which tend to be more sensitive to graphical presentations. Technology can be used to display and record a wide range of examples of visual stimuli and response variations (eg. Nally *et al*, 2000; Williams *et al*, 2002).
- Usually, interventions based on technology do not require high levels of social skills. This is particularly important for individuals with ASD, who typically present with a deficit of social skills (Reichow & Volkmar, 2010) and often experience discomfort within non-controlled social environments (Charlop-Christy *et al*, 2000).

- Individuals with ASD exhibit difficulties in situations involving environmental change, typically referred to as deficits in disruptive transition behaviour (APA, 2000). Technology-based interventions can be used to provide controlled responses and therefore serve as an efficient medium to present optimal, adaptive learning contexts while supporting the option to slowly and systematically increase the levels of complexity (Bolte *et al*, 2010; Golan & Baron-Cohen, 2006).
- Finally, the use of technology-based interventions can strengthen the internal consistency and reliability of research evidence since behavioural measurement in training (such as recording of sequences, correct responses or assessment of complex behaviours) can be easily standardised. This allows for more confident comparison of data sampled across learners and sessions (Morgan & Salzberg, 1992).

Video modelling

Video modelling has been suggested as an effective and technologically advanced method for developing a variety of skills in individuals with ASD (eg. Bellini & Akullian, 2007; Corbett & Abdullah, 2005; Delano, 2007; Kagohara, 2010; Nikopoulos & Keenan, 2006; Schreibman *et al*, 2000; Tereshko *et al*, 2010; Wang *et al*, 2011). It can be defined as the occurrence of a behaviour by an observer that is the same or similar to the behaviour shown by a model on a videotape (eg. Grant & Evans, 1994). The 'model' can be a peer, a sibling, an adult, or even oneself (Bellini & Akullian, 2007). The list of video modelling achievements is growing fast and includes, for example, teaching of generalised purchasing skills (Alcantara, 1994; Haring *et al*, 1987; Haring *et al*, 1995), daily living skills (Shipley-Benamou *et al*, 2002), conversational skills (Charlop & Milstein, 1989; Charlop-Christy *et al*, 2000; Sherer *et al*, 2001), social language (expressive) skills (Baharav & Darling, 2008; Charlop *et al*, 2010; Maione & Mirenda, 2006), generative spelling (Kinney *et al*, 2003), perspective taking (Charlop-Christy & Daneshvar, 2003; LeBlanc & Coates, 2003), socially relevant behaviours and play skills (Baharav & Darling, 2008; Blum-Dimaya *et al*, 2010; Boudreau & D'Entremont, 2010; D'Ateno *et al*, 2003; Dauphin *et al*, 2004; Gena *et al*, 2005; Hine & Wolery, 2006; MacDonald *et al*, 2005; MacDonald *et al*, 2009; Nikopoulos & Keenan, 2003, 2004a, 2004b, 2007; Parsons, 2006; Reagon *et al*, 2006; Simpson *et al*, 2004; Sturmey, 2003; Taylor *et al*, 1999), iPod use (Hammond *et al*, 2010), generalised imitation skills (Kleeberger & Mirenda, 2010), or transitional behaviours (Cihak *et al*, 2010).

Further, with a particular focus on adolescents and adults with ASD,

research has shown that video modelling can be an effective and promising method for teaching self-help, daily living and laundry skills (Horn *et al*, 2008; Lasater & Brady, 1995; Van Laarhoven *et al*, 2010), employment-related social skills (Morgan & Salzberg, 1992) or vocational skills (Allen *et al*, 2010). In this last study, Allen and colleagues used video modelling to teach four young men with ASD to use a mascot (ie. WalkAround®) and entertain customers in a large discount retail warehouse. All participants had either limited or no previous employment history. Appropriate use of the mascot comprised of waving, shaking hands, giving high-fives, moving the tongue, tail, ears or eyes, and jumping or shaking its body. Initially, participants watched two versions of a video model twice – scripted and naturalistic – and then returned to the main aisle of the store. In the scripted version (1.5 minutes long), the mascot was shown engaging in each of the targeted skills in isolation. Target skills were demonstrated both from the perspective of someone outside the costume and from the point-of-view of someone inside the costume. In the naturalistic version (4.5 minutes long), the mascot was shown using each of the targeted skills in a large retail warehouse on a busy weekend afternoon in a variety of combinations and sequences. Results demonstrated that video modelling was an effective way to teach young adults with ASD to perform a vocational task in a social setting. Each participant learned to shake hands, wave and interact with customers by waving their eyes, ears, and tail in ways that customers and managers found pleasing.

Critically, apart from video modelling being reported in the literature as an effective method for teaching a variety of skills to individuals with ASD, emerging evidence has suggested its effective use for eliminating challenging/problematic behaviours in children (eg. Nikopoulos *et al*, 2009; Schreibman *et al*, 2000). However, it has never been investigated as an approach for reducing challenging behaviours in adults with atypical development. This could possibly be achieved when potential reasons for the manifestation of challenging behaviours are identified and carefully considered and included in the construction of the videotapes. Thus, a functional behavioural assessment (FBA) procedure (eg. Bachmeyer *et al*, 2009; Delfs & Campbell, 2010; Dwyer-Moore & Dixon, 2007; Hanley *et al*, 2003; Manente *et al*, 2010; Matson & Wilkins, 2009; Matson & Minshawi, 2007) is initially conducted and the findings from it are used for the design of the videotaped scenarios. In a hypothetical example, functional behavioural assessment has suggested that the function of an individual's verbal aggression is to get attention from a member of staff during lunch. Based on this suggestion, in the video the model will be shown performing

an appropriate behaviour (verbal or gestural) in order to get the attention from the member of staff. A functional behavioural assessment is a precise description of a behaviour, its context, and its consequences, with the intent of better understanding the behaviour and those factors influencing it. It includes three approaches to assessment:

1. **Indirect assessment** consisting of structured interviews and checklists which have been developed to solicit information about situations in which problem behaviour occurs.
2. **Direct descriptive assessment**, involving direct observation of behaviour and the environmental situations in which it occurs. Opportunities are scheduled to observe and describe the target behaviour across a broad sample of environments and occasions with a focus on identifying functional relations between the target behaviour and the environment based on the A-B-C recording form (A: antecedent, B: behaviour, C: consequence). That is, an observer enters data whenever problem behaviour occurs: time and setting, problem behaviour, and events occurring immediately prior to and following the target behaviour. The data collected from these observations are analysed and one should look for trends in the occurrences of that behaviour, for stimuli that may be evoking it or the needs that the individual is attempting to fill by exhibiting this behaviour.
3. Finally, **experimental functional analysis** involves the systematic manipulation of environmental conditions in an artificial setting, to identify the variables that control and maintain challenging behaviours. Experimental control is deemed to be evident when a change in condition brings an associated change in behaviour (eg. Harvey *et al*, 2009). Although generally considered superior to other functional assessment methods, experimental functional analysis has known practical limitations and therefore it may be used only when data from the other two approaches are insufficient for the creation reliable hypotheses.

Computer-based training for individuals with ASD

According to a number of findings reported in the literature, the design of any computer-based device and program would involve a task analysis whereby the complex sequence of behaviours (tasks) in any given scenario are broken down into constituent elements in an effort to tailor the demands of the task to the individual needs of each child. This systematic

manipulation of the tasks would follow the rules of the scientifically validated strategy of Task Analysis (Baily & Wolery, 1984; Stokes *et al*, 2004). That is, a rather difficult scenario will be made easier by allowing children to experience selected parts of it (cf. *prompting*). Once the required behaviours in these parts are identified they can be taught to that child and the task of reconstructing the entire scenario for the child can begin. Undoubtedly, such training will also empower the treatment providers and/or parents of each child by learning how difficult behaviours can be effectively taught to their children with ASD (Keenan *et al*, 2000).

Computer-based programs and devices can allow the presentation of a simplified social environment and then a gradual increase in the complexity of social interactions. These are significant elements for the design of successful therapeutic programmes for children with ASD (Duquette *et al*, 2008; Goldsmith & LeBlanc, 2004; Robins *et al*, 2004b). In that sense, computer-based programs and devices could definitely be integrated into overall therapeutic programs, especially when they meet the following requirements:

1. Provision of multiple opportunities for children with ASD to imitate modelled behaviours should be a core component of any therapeutic program.
2. Any effective program should not demand the acquisition of advanced technical skills from the carers or treatment providers.
3. Multisensory interactions (auditory and visual information), controlled and structured environments, use of multi-level interactive functions, individualised use and independence, direction of observation to salient points are features that facilitate learning of children with ASD when working with computerised devices.
4. Any program has to be designed and conceived of as a set of rules that build on learning experiences in small logical steps (task analysis), progressing at a rate tailored to the needs of each child and incorporating immediate consistent consequences (eg. positive reinforcement) for responding.
5. Integral data collection is essential for assessing and monitoring children's progress.

Virtual reality/virtual environments

An area of application still in its infancy is the use of virtual reality (VR) environments in social skills training for individuals with ASD. Early studies have suggested that using interactive computer software could encourage language use (Colby, 1973; Goldenberg, 1979) and responsivity (Frost, 1981; Geoffrion & Goldenberg, 1981) and some suggested that social skills acquired in this way can generalise to other areas (Panyan *et al*, 1984). Children with ASD were reported as being more enthusiastic when working with computers than in a 'regular toy situation' (Bernard-Opitz, 1989), probably because the computer may appear to make fewer demands on them than a human tutor (Jordan, 1988), and reduce stimulation to a level of input tolerable to the individual (Strickland, 1997).

One of the first reports on its application described two case studies to investigate the use of VR as an aid to learning in children with ASD. Neither child was classified as having high-functioning ASD and neither spoke nor understood many normal sentence structures. The two children were given an initial test involving recognising and tracking a moving car in a street scene. Neither had previously been able to learn to recognise and track a common object when taught in the conventional way. Both children were happy to practice this task in a virtual street scene on a head-mounted display, and the explanation given for their improvement on the task after the intervention was the controlled nature of the learning environment, which limited the stimulus load on the learners. It may also have helped that the children with ASD were not exposed to social stimulation while learning the task in the virtual environment.

The controlled nature of the learning environment was one of the reasons behind the creation of 'Returning Home' (Charitos *et al*, 2000), which presents children who have ASD with possible everyday activities that may take place when they return home. The house consists of five rooms, for example, a bathroom and kitchen, on two stories, and before attempting a task, such as washing hands, the child has the option of watching an avatar perform the tasks. As yet, no findings have been reported using this application.

Parsons and Mitchell (2002) make a strong case for utilising virtual environments (VE), in social skills training for people with ASD in spite of the inherent contradiction involved in using a training medium that reduces the need for social interaction. People with ASD have little aptitude for pretence so sometimes cannot role play, but VE provide an opportunity

to learn rules and basic skills, which can be repeatedly practiced before entering the real setting in which they are required (Volkmar & Klin, 2000).

This approach was tested in a study with a group of six teenagers with ASD, some of whom had an IQ in the intellectual disability range (Leonard *et al*, 2002). As a baseline assessment, they were shown a video of a real café and bus interior, and were asked to choose where they would sit and why. They then underwent an intervention in a virtual environment depicting a café similar to that shown in the video. They had to learn two rules about finding a seat: 'when there is an empty table, you should sit there rather than with strangers;' and 'when there are no empty tables, you should ask if an empty seat is available or whether you can sit down'. The participants were then reassessed on the video task, and the remaining participants learnt the rules in the virtual café before repeating the video task. After training in the virtual café, the participants showed a significant improvement in ideal behaviour and in the social appropriateness of the reasons given. However, they could not generalise the rules from the café to the bus.

Strickland identified a series of VE characteristics that justify its use by individuals with ASD:

- VE can isolate children with ASD from their surroundings to help them focus on a specific situation.
- The complexity of a VE scene can be controlled.
- VE technology allows for the successive and controlled adjustment of an environment with the aim of generalising activities at different but similar settings.
- VE can be realistic, easily comprehensible, and at the same time less hazardous and more forgiving than a real environment when a mistake is made by the user.
- The present state of VR technology focuses on visual and auditory instead of haptic (touch) or other sensory stimuli. Specifically for ASD, vision and hearing have proven to be very effective in the development of abstract concepts (Jordan & Powell, 1990).

In addition, VE may be useful especially for children with ASD because of the facility they offer for aiding mental simulation through the process of experiential role play.

This application of rehabilitative VE could be criticised for exactly the same reasons that computer-based instruction for people with ASD has been criticised. Chen and Bernard-Opitz (1993) raised the possibility that computer-assisted instruction might be a hindrance to the development of social skills. To counteract this, software could be used with a teacher sitting alongside (Cromby *et al*, 1996). Howlin (1998) speculated that an over-reliance on computer interaction could lead to obsessive behaviour and a decline in real world interaction. The predictability of the software and the sense of control this may give could become appealing. Latash (1998), talking about a variety of users, warned that, if the rehabilitative VE is too safe and attractive, the person might be reluctant to re-enter the real world. Parsons and Mitchell (2002) advise that, to counteract this, VE could be made more flexible, with more interaction being demanded so that the VE is less predictable.

Robotics

Teaching of socially relevant behaviour to children with ASD through robotic tools is an area of emerging interest (eg. Barakova *et al*, 2009; Billard *et al*, 2007; Robins *et al*, 2004a, b, c). Anthropomorphic (human-like) or zoomorphic (animal-like) shaped autonomous robots have become of special interest. Since recent studies have indicated that robots may have a great potential in the therapy of children with ASD (eg. Dautenhahn & Werry, 2004; Michaud & Théberge-Turmel, 2002; Pierno *et al*, 2008; Werry *et al*, 2001a). Furthermore, robots may provide an opportunity for their use as a replacement of a parent/caregiver or therapist in the delivery of intervention (Barakova & Lourens, 2010). In most studies, robots perform simple behaviour with the purpose of provoking reciprocal human reaction.

Initial efforts: The AuRoRA project

The majority of the investigations in the area of robots come under the AuRoRA project (Autonomous Robotic platform as a Remedial tool for children with Autism), which started in 1998 and is led by Professor Dautenhahn (Werry & Dautenhahn, 1999). Its ultimate goal has been to explore the design space of interactive systems and to develop a socially interactive robotic system as a therapeutic tool for children with ASD (Dautenhahn & Werry, 2000). Thus far, within the AuRoRA project there have been three core studies and a few ancillary ones (eg, Robins *et al*, 2006) using:

1. An autonomous non-humanoid mobile robot (like a toy truck with heat sensors that could detect nearby children and had bumper switches that allowed it to reverse upon impact; Dautenhahn *et al*, 2003; Werry *et al*, 2001b).
2. A small stationary humanoid doll robot (an off-the-shelf doll with added motors, sensors and a simple processor that allowed the doll to move, sense movement, and even recognise gestures and respond to them (Robins *et al*, 2004a, 2004c; 2005a; 2005b; Billard *et al*, 2007).
3. A touch-sensitive screen (Davis *et al*, 2006).

An autonomous non-humanoid mobile robot

In a series of trials, children with ASD were given the opportunity to interact with a mobile robot called Labo-1. The robot was able to move in any direction on the floor, avoiding obstacles, including people, following a heat source and generating simple words and phrases. The children, aged 8–12, could approach, avoid, pick up, or even ignore the robot and walk away, or just lie on the floor. Basically, in a supervised setting, the robot would follow and be chased by the children, while at the same time producing brief utterances for those children who were able to respond to speech.

A small stationary humanoid doll robot (Robota)

The humanoid robot Robota was designed to cover the main limitation of the non-humanoid robot initially used in the AuRoRa project, which offered only a very small number of interactions with the child, such as spatial approach/avoidance turn-taking games. Thus, this small humanoid doll robot can further provide additional means of interaction, such as mimicking movements of body parts (eg. hands, head) and even more complex interactions (sequences and combinations of actions). It can move its arms, legs and head; however, it cannot move from place to place and cannot readily be picked up. The idea has been based on the assumption that bodily interaction in imitative interaction games is indeed an important factor in any child's development of social skills, and hence, teaching of such skills in a playful and exploratory way might help children with ASD in coping with the normal dynamics of social interactions. In a series of sessions in which, overall, 14 children with ASD aged 5–10 years old participated, Robota was dressed in a plain costume, and had simplified head features and was able to: 'dance' to pre-recorded songs; detect vertical

arm movements of the child and therefore to respond by lifting the right, left or both arms; learn and replay the action of a child when moving his/her limbs and the head.

A touch-sensitive screen (TouchStory)

This study used a touch-sensitive computer screen to explore ideas of narrative comprehension and expression in ways which were not necessarily verbal or textual. It differed from the ones mentioned above in that, while the child was free to stand or sit, he/she should be able to touch the screen or physical game and hence, interact with it. It also differed in that it was task-based in that the children were invited to play the game. Twelve children with ASD who were aged between five and 11 participated in a study wherein they were invited to make four stories with either laminated picture cards or draggable pictures on a touch-sensitive screen. It was seen as a collaborative task in that the experimenter gave the child feedback and if a wrong picture was chosen the child was invited to try another one. There was also an adaptive phase where the stories presented by the system varied depending on the interaction history with a particular child.

Collectively, and across a number of trials, the main findings of the AuRoRa project were that:

- the robot was safe for the children to use and most children were not afraid of the robot
- children interacted with the robot over a continuous period of five to 10 minutes or even longer
- children generally showed an interest in the robot (in terms of gaze, touch, physical proximity etc.) and were more engaged in interactions with the robot than with another non-robotic toy
- children played some imitation games with the robot (ie. the robot imitating children's body movements)
- in some cases, the children used the robot as a mediator or an object of shared attention in their interaction with their teachers
- the embodied nature of the robot allowed for the displays of body orientation and movements in ways that a two-dimensional display on a computer screen may be unlikely to evoke

- children might lose interest in interacting with the robot over time if it was exhibiting the same behaviour
- children were notably more social and pro-active when interacting with simple robots with few features.

Two recent developments: 2005 to present

Related to the AuRoRa project, a few more studies have been mentioned in the literature. These also focused on the investigation of human–robot interaction in the treatment of children with ASD. In 2005, Okada and Goan developed a creature-like robot, Muu, to observe how and whether children with ASD can spontaneously collaborate with the robot in shared activities, such as arranging coloured blocks together.

A couple of years later, Liu *et al* (2007) proposed a framework for a robot that might be capable of detecting and responding to affective cues with the view of helping children with ASD to explore the social interaction dynamics in a gradual and adaptive manner. In another study (Kozima *et al*, 2007), longitudinal observations of children with ASD interacting with a creature-like robot, capable of expressing attention by orienting its gaze and expressing emotions by rocking and/or bobbing up and down, were reported. Findings indicated that children spontaneously approached the simple robot and they not only engaged in dyadic (two-way) interaction with it, but they extended to triadic (three-way) interactions, including their adult caregivers. It was assumed that the minimal expressiveness of the robot facilitated social interaction by enabling the children to comprehend socially meaningful information. Similar suggestions were made by Scassellati (2005) and Duquette *et al* (2008), who found that children with ASD could perform positive preliminary social behaviours, such as touching, vocalising at, shared attention (visual contact, physical proximity) and imitate facial expressions (smile), when interacting with a simple robot.

Since 2008, an on-going development in this area has been a child-sized humanoid robot called KASPAR (Kinesics And Synchronisation in Personal Assistant Robotics) (Adaptive Systems Research Group, 2008), developed by the Adaptive Systems Research Group at the University of Hertfordshire under the lead of Professor Dautenhahn. The goal of this €3.22 million European IROMEC project has been to develop a reliable robot that can

empower children with disabilities to discover the range of play styles from solitary to social and co-operative play. Although this work has gained great popularity in the media, there is only one written report, which is in German.

In 2009, Kozima *et al* developed a simple robot, Keepon, which was shown capable of facilitating triadic interactions between itself, an infant with autism, and another individual (another child or the infant's parent/caregiver). Although the interaction of hundreds of children with Keepon has been conducted and recorded over the recent years, only very few children with ASD have been included in this sample. In the same year, Costa and her colleagues investigated the use of a non human-like shape robot – LEGO MindStorms NTX – for improving the social life of adolescents with cognitive impairments, ASD and mental disease. During five sessions, two adolescents diagnosed with ASD and developmental disorder experienced a robot which was able to execute a predefined simple choreography only when either its touch sensor was pressed or when a certain sound (music, clapping, among others) was higher than a predefined value. Results were mixed and the participants behaved differently concerning the interest in maintaining the interaction throughout time. Similar results were obtained when the same robot, but with a human-like shape, was used in a subsequent study by the same investigators (Costa *et al*, 2010). Lego robots were also used in a classroom setting in an effort to foster collaboration among children at the higher-functioning end of the autistic spectrum, obtaining promising results (Wainer *et al*, 2010).

The most recent development in the area has been described in a study by Giannopulu and Pradel (2010) wherein they analysed the interactions of four children with ASD, aged 4–7 years old, with a mobile toy robot that provoked the child to engage in free spontaneous game play. Interestingly enough, the rather small cylindrical-shaped mobile robot called GIPY1, had been homemade. Specifically, a representation of a neutral facial expression constituted the cladding of the robot; the round eyes and the triangle nose were dyed olive green and the elliptical mouth was dyed red. Everything was covered with a transparent plastic sheet. According to the authors, the simplicity of the robot was driven by reports that indicated that children with ASD perform better when engaging in play with simple and predictable toys. The robot could move forward, backward and turn on itself at low speed via a wireless remote control, facilitating chasing games with the participants. Results were consistent with those from previous studies, in which narrative description of robot-child interaction has mainly been utilised. Nevertheless, a notable aspect of this study was the calculation

of the exact duration of robot–child interactions during spontaneous game play based on four criteria; eye contact, touch, manipulation and posture.

Parents and healthcare professionals regularly report that individuals with ASD are drawn to technological devices and researchers have noted the importance of devising treatments that take advantage of this population who have a tendency to better use and learn from visual instructions (Goldsmith & LeBlanc, 2004; Konstantinidis *et al*, 2009). Moreover, the suggestion that children with ASD are mainly attracted to systems of low or minimal variance or even predictable (ie. technological devices/machines) (Baron-Cohen, 2006; Nadel *et al*, 2004) comes in accordance with the nature of robots, which can allow properties of repeatability and stability as well as predictability of repetitive and monotonous behaviour (Michaud & Théberge-Turmel, 2002).

Robots can further allow the presentation of a simplified social environment and then a gradual increase in the complexity of social interactions. These are significant elements for the design of successful therapeutic programmes for children with ASD (Duquette *et al*, 2008; Goldsmith & LeBlanc, 2004; Robins *et al*, 2004b).

The popularity of technology in the field of psychology is evidenced by the development of new journals in the area, such as the *Journal of Special Education Technology*, the *Journal of Educational Multimedia and Hypermedia* and the *Journal of Computer Assisted Learning*. Furthermore, Autism Speaks, one of the largest international autism funding bodies, continues to support an Innovative Technology for Autism Initiative promoting collaborations among healthcare professionals, computer scientists and designers within the ASD community. More traditional clinical psychology journals are also recognising the importance of technology in facilitating service delivery and as such are devoting special issues to the topic (eg. *Autism: The International Journal of Research and Practice*).

Last but not least, the use of technologies is becoming more mainstream because they are widely available, cost effective and easier to use, which warrants extending and combining them to address the task of helping people with ASD.

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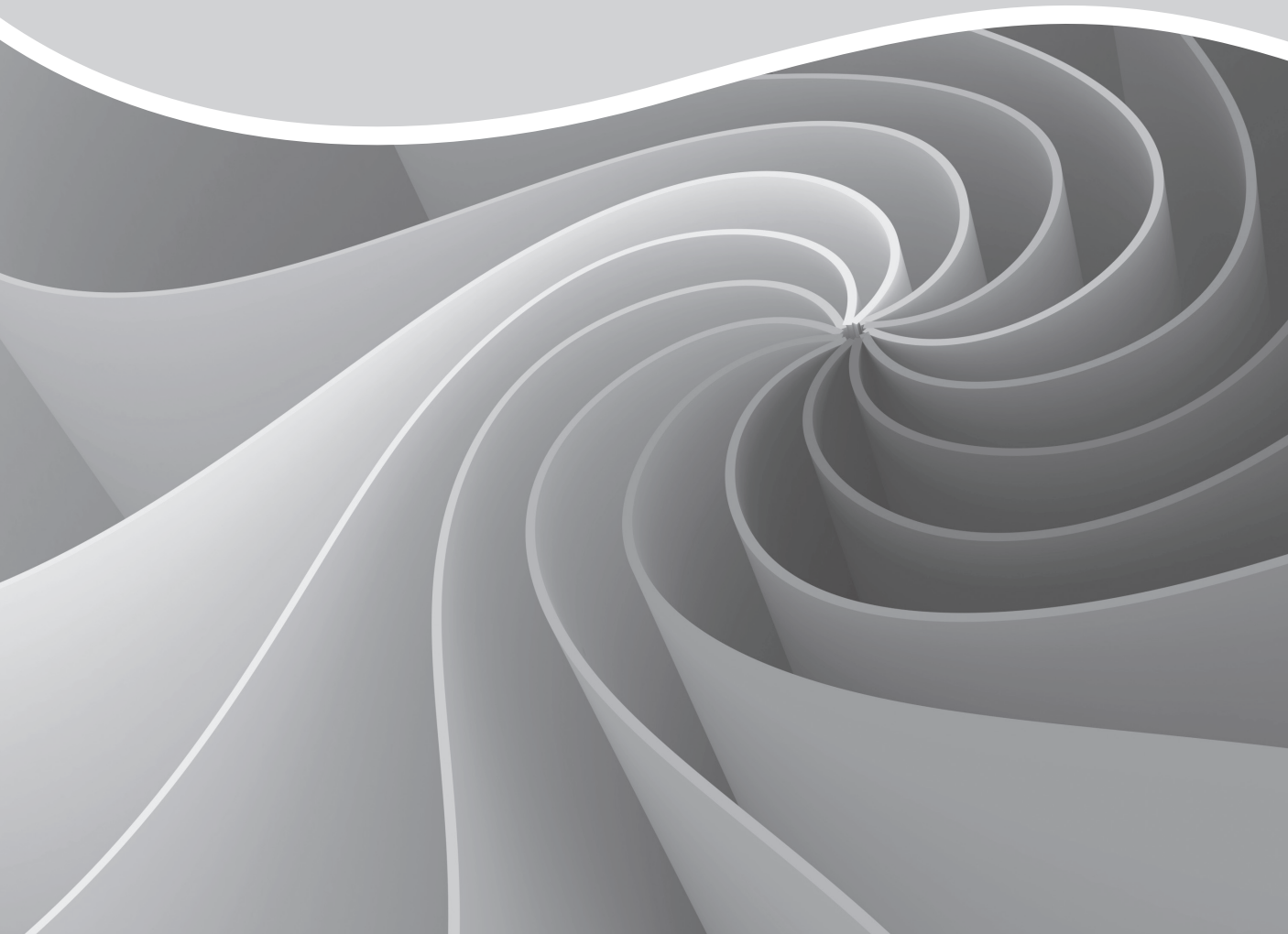
Part 5:

Offending, risk and research



Chapter 15:

Autism and offending

Huw Thomas and Jane Radley

Introduction

This chapter will explore the links between autistic spectrum disorders (ASD) and offending, before discussing the consequences for people with ASD who offend and describing the treatments and support available to help them.

Background

It is currently unclear whether offending is more common among people with ASD or not. There have been a number of high profile cases reported in the media of offenders who are said to have ASD, such as the case of Darren Harkin who killed his baby brother and subsequently escaped from a secure hospital and raped a 14-year-old girl. There are a number of individual case reports (Mawson *et al*, 1985; Baron-Cohen, 1988; Mukaddes & Topcu, 2006) and case series (Barry-Walsh & Mullen, 2004; Woodbury-Smith *et al*, 2006; Schwartz-Watts, 2007) of people with ASD who have offended.

Studies of the prevalence of ASD in offender populations have tended to find higher rates than would be expected. Scragg and Shah (1994) reported a prevalence of 1.5–3% in high secure hospitals in the UK and Hare *et al* (1999) reported a prevalence of 1.68% in the same institutions. A study in Whitemoor Prison reported a prevalence of 2.7 to 8.3% in the dangerous and severe personality disorder unit (Hawes, 2003). However, a study in Scotland reported that there was no increased prevalence in Scottish prisons (Myers, 2004). These findings could, however, be explained by other factors apart from an increased rate of offending, such as people with ASD being more likely to be placed in such services or having longer lengths of stay. A study of adolescent offenders in Sweden (Siponmaa, 2001) also found a very high incidence of ASD of 15%. However, a study in

Denmark (Mouridsden *et al*, 2008) reported lower rates of conviction, as did Woodbury-Smith (2006) in a community sample in the UK.

People with ASD can be conscientiously law abiding, with a rigid adherence to explicit rules and codes of conduct. Nevertheless, the individual clinical features of ASD undoubtedly contribute to offending in some people, and where this occurs it is important to understand the link between the disorder and the offence. This has implications for how the case is dealt with by the criminal justice system as well as health and social care services.

There is evidence that ASD is receiving increasing recognition within the criminal justice system, and is more likely to be used by the defence to influence the verdict and sentencing (Katz & Zemishlany, 2006; Schwartz-Watts, 2007)

Nature of offending

Whether or not people with ASD in general are statistically more or less likely to commit offences than the rest of the population, the type of offences they commit appears to be different. The following paragraphs detail some common offences and how they may relate to people with ASD.

Violence

Violence is the commonest form of offending in people with ASD (Woodbury-Smith, 2006). Violence may be impulsive or instrumental and the commonest age for this appears to be adolescence, a time of particular turmoil and difficulty for individuals with social and communication problems.

Case example: How violent offences can be atypical

One teenager, who was experiencing bullying at school, had an argument with his parents and picked up a kitchen knife and threatened them. He then ran out of the house into the village, where he met a young person from school who had been bullying him, and stabbed him, seriously wounding him.

Sexual offending

Sexual offending may take the form of sexual assault, rape, indecent exposure, voyeurism and harassment, including sexual offences against children. This may result from a wish for closeness and intimacy, combined with an inability to form normal social relationships with adults. Children may become the victim of an offence simply because they are vulnerable or because people with ASD may find that their emotional level is similar and may not be aware of the inappropriateness of such contact.

Arson

Fire-setting offences are more common than would be expected in the general population or in offenders with mental disorders (Hare, 1999; Siponmaa *et al*, 2001). Arson may be impulsive or instrumental and the motivation may be revenge, entertainment or difficulty coping with change. Many of these offenders have a special interest in fire or in fire engines and have a history of setting fires as children. They may choose to set fires out of anger, to gain revenge on people, for example family members or people living in the house who they dislike.

Case example: Fire-setting in a person with ASD

A young man was placed in residential accommodation for people with mental health problems. He wanted to be friends with the other residents, but they found his odd, stilted conversation and intense interest in witchcraft difficult to understand, and laughed about him among themselves. He set a fire, believing that he could cast a spell on them (Radley & Shaherbano, 2011).

Drug-related offences

These are rare among people with ASD but they do occur (Allen, 2007). Drug use may result from a wish to reduce levels of anxiety and may lead to drug dealing. Some instances may result from a wish to please or impress others, but currently there is little evidence to suggest that this is a problem for most people with ASD.

Computer-related offences

These types of offences appear to be relatively common in people with ASD as they may be unusually skilled in this area, are isolative and find it easier to communicate with people online rather than face to face. Their fixed moral opinions or lack of social skills may lead to unlawful behaviour.

Stalking/harassment

All five types of stalking identified by Mullen *et al* (2000) can and do occur in people with ASD. The 'rejected' stalker may be less common, as people with ASD are less likely to form romantic or sexual relationships, but when they do they may cope very badly when the relationship ends, resulting in inappropriate attempts to win back or punish the ex-partner. 'Intimacy seeking' stalkers are attempting to establish a loving relationship or close friendship with the object of their unwanted attentions, who may be a peer, a professional contact such as a teacher, or a public figure; this is relatively common in people with ASD because of a need for intimacy combined with poor social skills. They believe that the object of their attention will welcome their attentions. 'Incompetent suitor' stalkers are similar but stalk strangers in order to try to establish a relationship. They are often fairly easily discouraged but will then go onto harass another person. 'Predatory' and 'resentful' types of stalking also occur.

Features of ASD linked to offending

In specific cases it is useful to consider how the individual psychology of a person with ASD has led to offending behaviour. The following features of ASD may contribute to the risk of offending.

Poor planning and perspective taking

People with ASD may not automatically consider the chain of events which could follow from a particular act, or how their actions could be perceived by others. A young man with ASD broke into a building as he was feeling suicidal and was thinking about jumping off the roof. He was seen and reported to the police. He was surprised to be charged with an offence and hadn't considered how his actions might be interpreted as criminal.

Impulsivity and anxiety

People with ASD may be unusually impulsive. In some cases this can be attributed to having co-morbid attention-deficit hyperactivity disorder (ADHD), or may be associated with high anxiety states. When under stress, some individuals may decompensate (sometimes referred to as 'meltdown') which can manifest as an explosion of indiscriminate anger and aggression.

Stress-induced psychosis

In some cases, people with ASD commit violent offences during an episode of psychosis, which is often an acute and transient 'stress-induced' psychosis rather than a process psychotic illness. Stressors are many and varied and include things which most people might be expected to cope with relatively easily such as changes of routine, as well as experiences which are stressful for anyone, but much more common for people with ASD such as sensory overload and bullying.

Exploitation

Many people with ASD have little experience of friendship in childhood and may crave acceptance and belonging, particularly as they enter adolescence. This can make them very vulnerable to exploitation, particularly as they may lack the social skills to exercise good judgement about the motives of others. A teenager with ASD thought he had finally found friendship and acceptance when he was invited to join a street gang. He was told it was a 'rule' of the gang that they had to carry knives and use them if they came into conflict with rival gangs. Having a very literal understanding of the importance of following rules, he did as he was told and fatally stabbed a teenager in a gang fight.

Excessive honesty

Although not incapable of lying, many people with ASD have a naïve and simplistic approach to telling the truth as they see it. This is especially the case with regard to socially acceptable 'white lies'. This may commonly cause offence and may make the person seem rude or callous, which can lead them into conflict. In some cases where there is joint responsibility for an act, the person with ASD may be the only one who 'owns up' to it, making them more vulnerable to prosecution than others.

Lack of understanding of social behaviour or literal adherence to rules

For people with ASD the optional approach to social rules can be at best confusing and at worst infuriating. This can lead to conflict and offending behaviour. A man with ASD learnt that the rule on the pool table in his local pub was 'winner stays on'. He became very angry when a man who hadn't won the previous game started using the table, failing to appreciate that in this case the winner of the previous game had indicated he didn't want to play any more by putting his cue down. A fight ensued and the man was charged with assault.

Failure to recognise social cues or non-verbal communication in others

Most people can avoid conflict if they wish to do so by reading and responding to the non-verbal communication of others. If someone's tone of voice or facial expression indicates that they are becoming angry, this provides a warning that an escalation of the conflict may ensue. For people who are poor at reading non-verbal communication, these warning signs can be missed and they can unwittingly find themselves in a violent situation.

Inability to accurately judge age-appropriate relationships

People with ASD may be drawn towards sexual relationships with people who are much younger or much older than them. This may reflect their own emotional immaturity or need for care and support. Where the attraction is to younger people, this can bring with it a risk of offending against minors, which may be increased by social naïvety.

Inability to form intimate relationships

Adolescents and men with ASD will very often have difficulty finding appropriate sexual partners as they are impaired by factors such as poor social communication, social isolation and lack of confidence. This is may lead to sexual frustration and related offending behaviour such as stalking or sexual assault.

Special interests

These may lead people into offending in a variety of ways. An intense desire to obtain items related to special interests may lead to acquisitive crimes such as shoplifting or other straightforward offences such as riding on trains without a ticket. More complex offending can result from unusual special interests such as in the case of Gary McKinnon whose desire to infiltrate US security systems was a result of his special interest in UFOs.

Dislike of change

Anxiety about changes in environment or routine can result in impulsive violent outbursts, or instrumental offending with the intention of restoring a more familiar situation. An example is deliberate violence towards a new carer in order to effect their removal and the return of more familiar carers.

Poor ability to communicate desires or effect change

The phenomenon of instrumental offending behaviour in order to achieve change, such as a move to a new placement, is familiar when dealing with people with intellectual disabilities, but also occurs in people with ASD who are unable to communicate their wishes effectively and have an impaired ability to effect change in more functional ways.

Holding grudges/resentment of others

Grudges may stem from previous negative experiences such as bullying at school, rejection, loneliness and isolation. Some people with ASD develop a negative attitude towards particular individuals, groups or the world in general. An interest in computers combined with a grudge provides the ability and motivation to develop destructive computer viruses.

Assessment and treatment

The assessment of people suspected of having an ASD who have offended should include a formal diagnostic assessment. Where possible, structured interviews such as the ADI-R, ADOS and DISCO should be used to obtain information from an informant as well as from the individual. Even in cases where the diagnosis might be considered obvious from the

history and mental state examination, such assessments provide detailed information about the individual, which can help with the planning and delivery of further interventions.

Once a diagnosis of ASD has been established, attention should be paid to the assessment of any co-morbid psychiatric disorders, which can also contribute to offending behaviour such as psychosis, ADHD and anxiety disorders. Risk assessment (which is discussed in more detail in the next chapter) can be informed by using standard tools such as the HCR-20 and SVR-20, but there may be additional areas to consider which are more specific to ASD (such as sensory sensitivities). Specific risk assessment tools for use with this group are not currently available.

The assessment of offenders with ASD can be further informed by observation of the person's behaviour and interactions if they are admitted to hospital. Assessment of educational and occupational skills will help with the planning of various therapeutic activities, as well as the individual's potential to access further education and employment, which can help provide future stability. There are a range of psychological assessments which can be used to build up a picture of the person's profile of abilities and attitudes, including cognitive assessment (IQ testing, tests of executive function), personality assessment and assessment of communication skills, which is best done by an experienced speech and language therapist. This information should then be brought together to produce a formulation. This will lead to planning an appropriate treatment package.

Some people with ASD who offend cope well with being in prison. It is predictable, with a clear routine. They can spend long periods of time alone and there are few social demands. They may be 'model prisoners'. Many others, however, experience bullying, anxiety and depression, and are vulnerable to exploitation and abuse.

There is little research on appropriate treatments for offenders with ASD. Strategies commonly used include explanation of the diagnosis, use of a therapeutic milieu, treatment of mental health problems, social skills training, empathy skills training, cognitive behaviour therapy, education and employment (Dein & Woodbury-Smith 2010). Many people with ASD resist attending group-based therapies because of social anxiety, and therapy may be best done individually or in small groups.

Prognosis

The prognosis for offenders with ASD is unknown although some positive reports have emerged from the recently established secure units for offenders with ASD. Poor prognosis in the past may be due to a lack of appropriate treatment. The length of stay of offenders in a survey of Broadmoor (Scragg & Shah, 1994) was markedly longer than that of other patients. Some offenders with ASD may be too rigid in their thinking style to benefit from psychological therapies which require people to learn new ways of thinking. Problems with 'theory of mind' will inhibit progress in treatments which require an ability to appreciate different perspectives. A poor working memory may make retention difficult and underlying processing difficulties may lead them to misinterpret reflections or challenges. Even when individuals appear to understand and learn from the therapeutic process, they are likely to have difficulties generalising their experience to other situations without sufficient support and practice.

Conclusion

There is no evidence that offending is more common among people with ASD but the pattern of offending is different. In addition, features of ASD such as poor social skills and particular special interests may contribute to the risk of offending. There is currently only anecdotal evidence for the value of particular treatment approaches; it is clearly important to assess the risk and it appears that multidisciplinary input is helpful. As with all people with ASD a predictable and structured environment is helpful and communication and social skills deficits need to be addressed.

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Chapter 16:

Risk management in autism spectrum disorders

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Introduction

What do we know when considering risk management for people with autism spectrum disorders? Media attention on those who come into contact with the criminal justice system may give the impression that the prevalence of offending is higher among those with autism spectrum disorders. However, the available evidence indicates that the association between autism spectrum disorders and violence is not as high as that of the association between mental disorders such as schizophrenia and violence.

To understand the evidence and compare characteristics of offending, researchers have tended to separate individuals with higher levels of functioning from those at the lower functioning end of the autism spectrum. Those with childhood autism, who have a lower level of functioning, appear to have a reduced prevalence of offending compared with the general population. Recent studies by Woodbury-Smith *et al* (2006) and Mouridsen *et al* (2008) indicate that the prevalence of offending is not likely to be higher compared with the general population among those on the higher functioning end of the spectrum. Evidence suggests that comorbidities may increase the risk of association with violence.

There are differences between the types of offences committed by individuals on the lower and higher functioning ends of autism spectrum disorders. Offences such as criminal damage appear more common among the lower functioning group with which repetitive and challenging behaviours are often associated. Offences including arson, sexual offending and stalking appear more common among the higher functioning group. The use of illicit drugs appears to be less commonly associated. Overriding

obsessions, misjudged relationships, innate lack of empathy, lack of ability to recognise fear, difficulties in accepting justice and taking matters into their own hands due to limited social understanding appear to be underlying factors for much of the offending behaviour.

It is important to remember that these are differences in types of and reasons for offending rather than evidence for increased prevalence. Murrie *et al* (2002) wrote that the majority of individuals with Asperger syndrome are scrupulously law abiding but that a small subset does come into contact with the legal system.

This chapter focuses on the principles of risk assessment and management of offenders with ASD at the higher functioning end of the spectrum. These individuals may be in hospital or custodial settings with a history of offending. Considering the differences in offending characteristics, risk management should take the specialist needs of this population into account.

Risk assessment

Management of risk in those with a history of offending should be based on assessment using a structured clinical judgement approach where suitable tools are available (DH, 2007). Risk assessment methods are well-established for those with mental illnesses such as schizophrenia across secure hospitals, hospitals and in community settings. However, this is still an evolving area when it comes to autism spectrum disorders, with little published evidence as to its implementation.

Risk assessments can be considered in two categories:

1. Actuarial risk assessments, which look at historical factors.
2. Structured clinical assessments which incorporate clinical factors that are usually dynamic at least in the short to medium term.

Historical factors include history of previous convictions, juvenile delinquency and supervision failure. Clinical or dynamic factors usually include level of insight, presence of acute symptoms and level of compliance that may change frequently in the short to medium term.

The risk assessment tools used in clinical practice include dynamic factors such as psychotic symptoms relevant to the particular offending behaviour,

measurement of improvement in psychotic symptoms, level of insight, presence of substance misuse, self-harm and compliance with medication. Structured clinical risk assessment methods such as Historical, Clinical Risk Management-20 (HCR-20), Short-term Assessment of Risk and Treatability (START), and other assessment tools are widely used, particularly in secure hospital settings for those individuals with autism spectrum disorders and other developmental disabilities with a history of offending behaviour. However, these tools were developed to be suitable for those with mental illnesses such as schizophrenia. They also assume a level of functioning that is expected in individuals without developmental disabilities.

Gray *et al* (2007) reported the HCR-20 to be a significant predictor of violence in people with intellectual disabilities in secure settings, with the historical sub-scale performing particularly well. Johnston (2002) wrote that, although several measures had been adapted, they were not validated. Since then, Lindsay *et al* (2008) compared the discriminative validity and the predictive validity of several actuarial and dynamic risk assessments. The study examined incidents among participants in three groups of offenders with intellectual disabilities who were patients in high, medium and low security settings. They reported that structured risk assessment tools (VRAG, HCR-20 and the EPS-Internalising) demonstrated significant discriminative validity and predictive validity in people with intellectual disabilities.

Standardised risk assessment tools such as HCR-20, START and specific tools such as Risk for Sexual Violence Protocol (RSVP) can be used meaningfully as long as additional factors that are relevant to the individual with autism spectrum disorder are taken into account and used to inform the risk assessment. More recent research has started to consider criminogenic variables which have established predictive validity in the general population. The Offender Group Reconviction Scale (OGRS; Copas & Marshall, 1998) is a criminogenic risk assessment tool for general offenders. Although there is little evidence of its use in people with autism spectrum disorder, it has shown good predictive validity when used with offenders who have intellectual disabilities (Fitzgerald *et al*, 2011).

Adapting risk assessment tools

When using risk assessment tools in individuals with autism spectrum disorders, additional consideration should be given to individual and offending characteristics, which act as predisposing, precipitating and maintenance factors for violent behaviour.

On examining common themes from a secure inpatient setting with individuals who have a primary diagnosis of autism spectrum disorder, the authors found the following themes emerge, underlying risk behaviour.

- Inability to seek appropriate course of action in response to perceived or actual difficulties caused by others, and reacting to such difficulties by means of violence which the individual thinks is appropriate justice. This is exaggerated by a difficulty to seek solutions by meaningful discussions.
- Inability to appreciate social boundaries, and engaging in inappropriate behaviour, sometimes combined with inappropriate sexual or other unusual interests/preoccupations. Misinterpreting events, rules and situations.
- Overriding obsessions, misjudged relationships, innate lack of empathy, lack of ability to recognise fear and difficulties in accepting justice and taking matters into their own hands due to limited social understanding.
- Passive aggression by refusing to co-operate, eat, speak, dress or attend self-care as a way of protest.
- Limited awareness of consequences of their actions to themselves or others.
- Presence of co-morbidity such as depression, anxiety or other mental disorders.

The above is not to state that these are the sole reasons, but an observation of characteristics that act as predisposing, precipitating and maintaining factors to risk behaviour.

Risk assessment should be individualised to include the particular characteristics that are associated with violent behaviour in the individual. The assessment should be multidisciplinary and carried out by people with experience and/or specialising in autism spectrum disorder. Rigidity in thinking, communication difficulties and perceived difficulties by the individual should be taken into account. Strengths and weaknesses of the individual should be considered, which would assist in planning support and management.

Many risk assessment schemes are based on the premise that presence of a mental illness, history of previous violence, substance misuse, psychopathy, delinquency, lack of insight and non-compliance are indicators for increased risk and future propensity for violence. When the mental illness considered is that of an autism spectrum disorder, the evidence

is less convincing that the presence of the disorder itself and the other factors that are established to have increased risk are fully applicable. Professionals assessing risk should avoid narrow interpretation of tools and consider the individual characteristics. A formulation of how the characteristics of an individual with autism spectrum disorder had been associated with violence should be considered.

For those detained under the Mental Health Act in secure settings, the assessment should take into account how the mental disorder (autism spectrum disorder) is associated with risks to self, others or health. These include the level of social and self-awareness, vulnerability, sensitivities, preoccupations and unusual interests, anxiety-provoking situations, obsessions/compulsions and level of communication. These characteristics should not be seen as risk factors themselves when they are not associated with violence and are not thought to be factors predicting violence. A number of these may well be protective factors in many of those on the autistic spectrum.

Risk management

A systematic risk assessment should be followed by a formulation of the risk behaviour(s) and a comprehensive management plan. Due to the diversity of characteristics and varying ability of individuals with autism spectrum behaviour, risk management plans are likely to require individualisation to a greater degree. Management plans may include targeted interventions in social interaction, communication and behavioural domains. Environmental modification, treatment of co-morbidities and utilising strengths of the individual are likely to be significant factors. An analysis of predisposing, precipitating and maintenance factors for the risk behaviour would guide the treatment interventions.

The interventions may include developing social awareness, work with family or carers, coping skills and developing alternative occupations. Co-morbidities such as anxiety, depression or other mental disorders may require medication.

A variety of characteristics can be seen as strengths in planning therapeutic interventions. Some people may prefer visual communication and some may have unusual sensitivities. They may be less able to recognise others' emotions. They may tend to isolate themselves. They may have some unique abilities; for example with numbers, musical instruments etc.

The majority of the individuals with autism spectrum disorders prefer a structured day with predictability. The difficulties may arise when there is a lack of structure, which makes them anxious. For example, someone with Asperger syndrome may have a history of becoming anxious when his or her routine is disturbed. Some may find it difficult to cope with noise. Some may have different preoccupations. Hoarding may present a fire risk. Some of the common themes such as social naïvety, difficulty in understanding social cues and difficulties in language may increase their vulnerability. Multidisciplinary teams should be informed by speech and language therapy assessments and support plans where applicable. A desire to be liked and accepted by others is present in many of those individuals which can be utilised.

Risk management plans should take individuals' strengths and weaknesses into account. Individuals may need assistance to understand the wider consequences of their actions eg. a person that engages in a vengeful act against a person or company may not be aware of how it is perceived by others. For example, as a protest against a local authority an individual with autism spectrum disorder puts excrement on public toilet walls believing it will inconvenience the council, but they may not be aware how this is perceived by others.

Best Practice in Managing Risk (DH, 2007) provides guidance on effective clinical risk management within mental health services. It also recommends that risk management should be embedded in day-to-day practice and as part of the Care Programme Approach (CPA). Risk management must be built on a recognition of the individual's strengths; emphasise recovery; have multidisciplinary involvement; and staff should have relevant training. The guidelines also state that the risk management plan should include a summary of all risks identified, formulations of the situations in which identified risks may occur, and actions to be taken by practitioners and the service user in response to crisis.

Xenitidis *et al* (2001) recommended a systematic approach to the identification of target behaviour, quantitative measurement of target behaviour, generation of hypotheses (medical, psychological and social) about the genesis and maintenance of the behaviour, delivery of therapeutic intervention, evaluation of effectiveness of the intervention and generation and testing of alternative hypotheses. This approach should form the basis for interventions and subsequent evaluations.

The following is a selection of brief case studies that illustrate some of the considerations when developing risk management plans for individuals with autism spectrum disorder who have a history of offending.

Case study: Alan

Alan was diagnosed with Asperger syndrome during early childhood and attended autism specialist schools. He had a number of care placements during childhood. Upon reaching adulthood, at the age of 18 he was convicted of a few offences, including theft (of chocolate) and threats to kill. Following a few months stay in a prison he was transferred to hospital settings where he remained until the age of 26. In hospital settings the difficulties continued, particularly from Alan's poor ability to compromise, negotiate and engage in socially acceptable behaviour. He did not engage in any therapy for several years and there were a number of incidents of property damage and other physical aggression. He was frequently moved between hospitals which reflected the difficulties in provision and lack of expertise available.

An examination of the offences committed by Alan revealed a pattern of difficulties in communication underlying the offences. In the last placement catering for individuals with autism, after identifying his difficulties the team moved to provide him with reassuring messages, reduce anxiety and support him to express resentment and to interact with others in socially acceptable ways. He made significant progress and was moved to a lesser secure setting. He did not show significant risk behaviour for several months and engaged in a number of therapeutic initiatives. All of these were possible with establishing a therapeutic relationship and acknowledging his difficulties.

He had difficulties in expressing himself and in understanding the perspective of others. For example, on a day when he was upset he would be very threatening and abusive to the very same professional he trusted but would be very caring the following day. He was able to recognise these difficulties cognitively and showed significant change in patterns of his behaviour. He worked on expressing his emotions in socially acceptable ways. From a position of being defiant to rules, he moved to working with professionals in therapies. The progress enabled a move to a community setting with family support.

Case study: Ben

Ben is a 25-year-old male with Asperger syndrome. He presented as socially naïve and his use of language showed literal interpretation. He was diagnosed with Asperger syndrome at a young age and attended a special school at secondary level. He gained some qualifications after school but struggled with jobs and was sacked several times. He was convicted of arson aged 20 after he set fire to some objects to watch them explode, for which he received a community sentence. A year later he was convicted of harassment as he wrote several letters to others in a threatening manner. He had unusual ways of showing resentment. On one occasion he tried to mix cleaning liquid to a drink and on another he piled up objects to obstruct the entrance of a shop that he had been sacked from for having poor customer skills. He did not know how to negotiate in socially acceptable ways and had a poor appreciation of others. He had some preoccupations including an interest in certain cartoon characters.

He was transferred to hospital from prison and in hospital his difficulties in reciprocal social interactions continued. He wrote letters of threats towards staff members and peers. He was socially naïve and vulnerable despite a high IQ. However, he was cognitively able to understand right and wrong and appreciate what was socially appropriate when explained. The risk assessment took into account the characteristics of his Asperger syndrome including particular preoccupations, poor understanding of social cues, socially inappropriate expressions and deficient empathy.

With acknowledgement of his difficulties, he attended programmes to increase his social awareness. He worked on acceptable ways of showing resentment and other communication. He made progress with graded leave to community and participation in occupational schemes. After a hospital-based work placement, he commenced work in jewellery making and was eventually discharged with support in the community.

Case study: Callum

Callum is a 21-year-old man with a history of being in residential school settings for a few years during adolescence. There were no family members or friends in contact with him. He was diagnosed with Asperger syndrome at school and displayed difficult behaviour. Following assault on one of his parents and breaking into their house, he was detained aged 17 and was admitted to a hospital.

He presented with significant egocentricity, poor appreciation of social boundaries, poor self-care and difficult interactions. He was argumentative and had a high IQ, which played a role in his ability to maintain his arguments, which were ultimately to his detriment. He would argue that passive aggression was right because 'Gandhi did it' and aggression was OK 'because that's how problems have been solved in history'. He presented with very poor negotiating skills in that he was unable to appreciate or accept another party's point of view.

He did not have meaningful goals regarding the future. He presented with challenging behaviour in unusual ways. This had included escaping from a secure hospital on a few occasions only to stand outside the hospital waiting for staff, saying that he wanted to prove he was not trying to escape.

He engaged in conversations for prolonged periods only to present with arguments to justify why he was right in his actions and how the systems were wrong. He had rejected any long-term structured therapy; not accepting the goals. The care team's first approach was to explain to him that he did not have to prove his knowledge or that he was skilled, but the aim of detention was that of risk reduction, which appeared to help.

Callum's self-care and social interactions were very poor. He was sensitive to noise. There was also a history of certain preoccupations, obsessions, ritualistic behaviour, sensitivities and body movements. Callum's risk assessment included identification of his characteristics including egocentricity, passive aggression and poor appreciation of social norms.

The risk management plan recognised his sensitivities and vulnerability. The management plan included providing him with unambiguous messages and supported him to express himself appropriately. He was encouraged to pursue meaningful goals. When he challenged any ward rules, the reasons for these rules were explained to him and he was given a rationale for social boundaries. His co-operation and relationship with others improved gradually and he progressed well into the community with support.

Conclusion

As discussed in this chapter, risk assessment in individuals with autism spectrum disorders should include examination of individual autistic characteristics and risk formulation. There are autistic traits that each individual displays idiosyncratically and it is essential they are taken into account in risk management. The treatment and management of offenders is not only offence specific, but will include attention to other areas such as education and skills development, which might reduce the risk of future offending. Multidisciplinary input in identifying risk factors and in formulating risk management plans is essential to risk reduction. Finally, risk assessment tools are an aid to clinical decision making, not a substitute. Care teams should consider how their risk management procedures could be improved by integrating the principles of risk assessment and utilising one or more of the tools into their overall approach.

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Chapter 17:

Advances in autism research

Richard Mills

Introduction

Looking forward, looking back

Individuals with autism have long been misunderstood, stigmatised and ill-treated. Sadly, much of this has been in the name of therapy. Labelled 'low-functioning', 'complex', 'challenging', we have seen people with autism excluded, punished or medicated. As the numbers diagnosed with autism increase, it is important that professionals in the field gain a true understanding of the condition and respond appropriately. High quality research is one means of achieving this.

Our current understanding of autism is indebted to those pioneers of autism research who were prepared to challenge prevailing views with arguments based not on armchair theory but science. The search for truth has been joined by the growing number of researchers now concerned with autism, many of whom are themselves on the autistic spectrum. Looking forward, robust and scientific discipline is vital in a field where speculative, unfounded or harmful theory remains prevalent and is enthusiastically promoted. Science can provide safeguards against quack theory and the approaches based upon it. However, to date, research in autism has often lacked the rigour seen in other branches of science and investment in research has not reflected the large sum of public money expended on autism. Moreover, research programmes themselves have too often been narrowly focused or have failed to address the priorities of the autism community.

Looking forward, partnership with this community in research is critical as is a real connection with non-scientists to ensure that the development of ideas and practice is based on the best available evidence.

Research in autism is about:

- systematic, impartial investigation to establish fact or produce evidence
- challenging existing ideas and reaching new conclusions
- protection against harm, bias or the self-interest of therapists.

Unlike in many areas of public health, the autism community is highly varied with incredibly diverse characteristics and needs, and due to this heterogeneity this is not a topic that can be easily defined for policy purposes.

Making sense of research

Newspaper reports of 'breakthroughs' in research are mostly unreliable and misleading. Scientific journals may be difficult for non-scientists to navigate and may be a barrier to translating research findings into practice.

When reading research papers concerning intervention it is important to consider the strength of the evidence and whether it has been published in respectable peer-reviewed journals. It is also important when assessing the claims made to look at the size of trial (how many people took part) and whether researchers were impartial. Anecdotal claims or findings based on small studies may be interesting but do not necessarily constitute evidence. What may help in one case may not in another.

There is a generally accepted hierarchy of research methods designed to produce best evidence; with systematic review and randomised controlled trials (RCTs) representing best evidence, with opinion and case studies worst (Greenhalgh, 1997). Historically there have been few RCTs in autism.

There are also problems with the methods used to evaluate interventions. Stated goals may limit the scope of intervention and may not be relevant to the specific individual. Approaches outlined in manuals may fail to account for heterogeneity. Randomised controlled trials may encounter problems in selecting or matching participants or there may be problems with how a treatment is actually carried out (known as 'treatment fidelity'). There are many other challenges relating to the overlap of other conditions.

Most professionals tend to be interested in pragmatic questions such as: what works and why? For whom does it work and what would make it work better?

Or what else works? The claim that an intervention is 'evidence-based' does not necessarily mean it will be suitable for the individual for whom it is being considered (Mesibov & Shea, 2011; Pellicano & Stears, 2011).

RCTs are important but expensive and difficult to set up. Sometimes, well-designed qualitative single case studies or case series evaluations involving a number of individuals may offer a practical and ethical way forward. They may also provide good data for further trials, but it is important to be alert to dangers of bias and placebo as they are not a substitute for larger trials. Particular care should be exercised when evaluators are aware of who has received an intervention and who has not (known as blinding) as this can create bias.

Evaluating the effects of a treatment on a number of individuals as part of a properly controlled trial constitutes what is known as an evidence-supported treatment, which can be measured and replicated. This differs from evaluating the effects of a particular treatment on one individual, which is known as evidence-based practice. This latter approach is effective where there is a variable presentation such as in autism (Mesibov & Shea, 2011).

Evidence-based practice therefore involves 'integration of best available research and clinical expertise within the context of patient characteristics, culture values and preferences' (APA, 2005) and while it may be important in moving the field beyond speculation, anecdote and fad, it must also be flexible and capable of evaluation.

In essence, evidence-supported treatments and evidence-based practices are intertwined and, looking forward, both should be integrated into any evaluation of an intervention.

What does research tell us?

Perspectives on autism: the current view

There is a consensus that the term 'autism' is used to describe a constellation of neurodevelopmental conditions with many causes. Presentation and outcome is highly variable. Individuals will have strengths as well as deficits. Co-occurring disorders are significant. Looking forward, it is likely that investigation of subgroups (the autisms) will increase with implications for more specific diagnoses and interventions (Spence & Thurm, 2010).

The question of IQ

Prior to the 1980s autism was almost always associated with intellectual disability. Criteria have broadened to include those with average or high intelligence. IQ tests which predominantly rely on verbal rather than non-verbal ability discriminate against the non-verbal strengths of the person with autism (Mottron, 2011).

Diagnosis: what are the implications for research?

Diagnosis and categorisation of behavioural symptoms is currently based on systematic observation and history. At present this is problematic as these are often imprecise as they are based on behaviours where there may be alternative explanations. As yet there is no neurological test for autism although research in this area means that early diagnosis may soon be possible through brain scanning. It will be interesting to see if this method also addresses two of the major difficulties relating to early diagnosis: consistency and stability over time.

The 'core' symptoms of autism comprise positive signs ie. the *presence of abnormal development* such as repetitive behaviours and a focus on detail or unusual visual or rote memory, and negative signs ie. the *absence of normal development*, such as language and social attachment. Other features may also be present such as anxiety, sensory processing problems, phobias and a marked resistance to change.

Classification of autism

The two main systems for classification are the *International Classification for Diseases (ICD)* and the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. Both are periodically reviewed and revised and new versions are expected in 2013. Both have criteria used for research to enable comparisons to be made between participants. There is concern that the revised criteria may exclude many who currently meet the diagnostic threshold.

Disorder or difference?

The debate as to whether autism is a disorder is an important consideration in research where tensions can arise between the autistic and research communities. There is a conflict around the perceived medical model of autism with its connotations of cure and treatment. Deeply resented by

many in the autism community, it remains a popular concept with many parents and some individuals with autism. The important question is whether research will lead to acceptance and improvement in quality of life or to further stigma and intolerance? Whatever the view, there is an obligation on professionals to alleviate distress where it occurs and provide help to overcome the barriers that autism may represent.

'Autistic thinking': a way forward?

Research into *cognitive theories of autism* enables us to glimpse the world from the autistic standpoint and develop empathy for this perspective. They have revolutionised education practice, yet their impact on social care has yet to see the same effect.

In summary, these theories are known as *theory of mind* – the knowledge that others have their own thoughts that are different from one's own; *executive function* – the ability to plan, organise and monitor, and *central coherence* – the ability to make sense of diverse or competing experiences to make a whole. These processes are typically impaired in autism (Frith, 1991) and help to explain why people with autism prefer structure, routine, consistency and predictability, and why they find the world chaotic, confusing and even frightening.

In forthcoming research, Baron-Cohen suggests that participants with autism are stronger systemisers (ie. knowing how things work) as opposed to empathisers (ie. knowing how people 'tick'). He suggests that this is a trait seen more commonly in males. (See www.telegraph.co.uk/health/9045703/Parents-provide-due-to-autism.html)

A further important aspect concerns that of context blindness (Vermeulen *et al*, 2012) where theory of mind and social skills may be intact but the person may struggle to apply them in the correct social context.

Autism and the brain: what do we now know about the brain and autism?

An understanding of the brain can help us to make sense of human behaviour and transform the way we perceive and work with people. We can refrain from negative judgements about the nature of behaviour if we see autism as a difference in the way the brain works, and not deliberately antisocial.

The impact of research in understanding the brain is therefore of critical importance. Specific brain structures and regions are known to be implicated in autism and some of the behaviours seen in autism. The corpus callosum,which separates the two hemispheres of the brain, the cerebellum – responsible for movement and learning, and the hippocampus – responsible for memory – have been implicated in autism but to varying degrees. There is mixed evidence as to whether it is the structures of the brain that are themselves abnormal or whether it is due to a faulty underlying physiological mechanism.

Other theories of interest include the brain cell pruning hypothesis, a natural process that in some cases does not occur in autism, leading to cell overgrowth in those areas of the brain concerned with arousal patterns,with knock-on effects associated with excitability, irritability and anxiety.

Research of the so-called 'social brain' is also promising. The amygdala, an important part of the social brain neural network underpinning social behaviour, is responsible for emotional states related to empathy. The amygdala has been seen to be anatomically abnormal in some individuals with autism (Brothers, 1990; Kemper & Bauman 1993; Baron-Cohen *et al*, 2000) but more recent animal studies suggest that such abnormalities may play less of a role in 'core' autism symptoms but are significant in fear responses and anxiety – both important in autism.

The prefrontal cortex of the brain is also implicated in many of the cognitive difficulties seen in autism such as theory of mind and a link with ADHD (attention deficit hyperactivity disorder).

The unusual memory pattern often present in people with autism with exceptional memory for facts coupled with a poor working memory would suggest the hippocampus is also important. The hippocampus is also involved in a number of the cognitive (thinking and responding) aspects of autism, particularly central coherence, that is, in processing diverse sources of information.

We also now know from research that the brain is not static and has an incredible ability to reorganise itself by forming new connections throughout life. This process, known as neuroplasticity, allows the neurons (nerve cells) in the brain to adjust their activities in response to new situations or changes in the environment and continues well into adulthood, which may be why so many positive changes are seen in many

autistic adults. The current emphasis on early intervention sometimes overlooks the fact that the brain continues to develop and mature beyond the early years.

At one time it was only possible to examine the brain at post-mortem. Although these studies are still very important, modern brain scanning techniques using Functional Magnetic Resonance Imaging (fMRI) and Diffusion Tensor Imaging allows exploration of the living, active brain. fMRI shows how the brain works by tracking blood-flow using a powerful magnet. When a participant is asked to perform certain mental tasks, the brain regions activate or 'light up' allowing researchers to record these events. This allows comparisons to be made between participants with and without autism. fMRI also shows functional differences between participants with and without autism in a part of the brain called the fusiform gyrus, which is associated with recognising faces and emotional states.

Developments in neuroscience have also transformed our understanding of how the brain processes information at a neural level. Diffusion tensor imaging allows us to track this by following the movement of water through the brain to demonstrate the strength or weakness of connectivity between the billions of neurons and supporting cells called glial cells. These govern the relationship between the various parts of the brain. These chemicals are called neurotransmitters and the junction where they connect is called a synapse.

Recent research has shown that neurotransmitter chemicals called glutamic acid (GA or glutamate), glutamine (GAM) and gamma-aminobutyric acid (GABA) are important in autism and seem to be controlled by genetic influences. GABA calms the brain and relaxes the body whereas glutamate has the opposite effect, exciting and stimulating the brain and concerned with memory. An amino acid, glutamine is responsible for the brain's energy and for regulating production of both GABA and glutamate. When unbalanced it is said that this leads to overstimulation of the brain, resulting in an inability to filter out stimuli. It also impacts on information and sensory processing, social responsiveness, arousal levels and memory. This may explain why different areas of the brain seem to be affected at different times and in different ways. Simplistically, it suggests interventions based on diet, supplements or other medications might be possible, but although GABA is well established as a treatment for seizures and depression, its absorption into the body is problematic.

Recent interest in so-called 'mirror neurons', responsible for imitation, has led to experimental interventions based on electrical or magnetic stimulation, but it is too soon to tell how effective these are.

Other research into the 'bonding hormone' oxytocin, produced by intense emotional experience, suggests that this may be deficient in autism. Experimental treatments are currently underway (Gordon & Pelphry, 2012).

It is anticipated that advances in neuroscience with larger trials and better techniques will continue to address some of the inconsistencies in current research, clarifying inconsistent theories of the brain in autism. Despite the technological advances in neuroscience there remains a need for post-mortem studies, but there is a current shortage of brain material for study, delaying vital research.

Autism and gene research: a 'gene for autism'?

Hans Asperger believed genetic influences were important and later studies of twins by Susan Folstein and Michael Rutter (1977) strongly supported genetic factors, but not the result of one single gene. The presence of autism-like symptoms in close relatives was also noted but while such individuals may possess a number of features of autism, now referred to as 'the broader autism phenotype', they fail to meet the threshold for diagnosis.

Advances in human genetics have identified that autism may be more related to genes plus other factors, such as paternal age, than to genes alone. As it is a variety of genes that are of interest – with multiple mutations – future research, possibly using mouse models, will examine how these disrupt the areas of the brain involved in social behaviour.

In many ways the search for regions of the genome that has susceptible genes has given way to an approach based on identifying specific genes to study their associations. These are known as 'candidate genes' and although several have been associated with autism, including with GABA, none has been consistently identified and as such there is no 'gene for autism'.

Autism and other conditions: why important?

Researchers now recognise the significance of those conditions that co-occur with autism in a majority of individuals with autism. They include high levels of anxiety and very high rates of psychiatric conditions, sensory processing disorders, other neurological disorders and physical problems. The MMR controversy conflated gastrointestinal problems and autism and although no link exists with MMR, recent research has confirmed a higher rate of gastrointestinal problems in children with autism.

At a clinical level it is important that all co-occurring conditions are thoroughly investigated, diagnosed and treated as they are significant in terms of their impact on health, well-being and outcome.

Numbers affected – how many with autism?

The 1966 study of prevalence by Lotter estimated four to five cases of autism per 10,000 people but included only those with intellectual disability. Following revision of the criteria, UK figures cite 116 per 10,000 – or around 1 in 100 (Baird *et al*, 2006). In the US, 1–88 per 10,000 is reported as affected, with wide geographic and demographic variations. (Centre for Disease Control, 2008) Such studies may provide useful leads on the nature of autism itself. A case is often made for routine total population screening for autism but at present the lack of precision on the clinical presentation of autism and the poor evidence on effective treatments do not support this – although screening of specific populations may be useful. Examples might include the criminal justice system, women and minority groups and the uptake of services (Mills & Francis, 2010).

Interventions: what works?

This chapter is unable to describe the many hundreds of approaches and interventions in use in autism. It is important to distinguish between those interventions designed to 'reverse' or 'cure' autism – the 'core' symptoms – and those that address specific behaviours, or improve adaptation, or treat co-occurring conditions.

Despite the many claims for effectiveness there is no evidence that any intervention will 'cure' or reverse autism. Moreover, there are very few interventions that have an adequate evidence base. Most studies – and therefore the strongest evidence – concerns intensive behavioural interventions, but even those with the strongest evidence base, such as early intensive behavioural interventions, are not universally effective. Recent studies have been methodologically better, but there are still many weaknesses in the research to date (Mills & Marchant, 2011).

Understanding the autistic mind has helped develop 'autism-friendly' systems of education and care. Approaches concerning modified cognitive therapies, regulation of emotional states and sensory-based approaches at present lack robust evidence, but are promising.

Psychotropic medications have been widely used to treat autism and autism symptoms such as aggression, restlessness and anxiety, but despite an increasing number of RCTs there is no supportive evidence for their effectiveness and serious side effects are reported (Siegal & Beaulieu, 2012).

Research into genetics and neurology may involve the development of novel drugs that interfere with underlying processes at a genetic or neural level, but the ethical issues raised are complex and these are very early days. In summary, no one intervention will suit all and hazardous and unproven treatments are still aggressively marketed. An individualised approach involving several different methods in a consistent and structured environment may offer a way forward, but only if they are humane and safe with and have been independently seen to help similar individuals.

Future advances must be concerned with the evaluation of the various models of education, care and services, where, despite their high cost, there has been relatively little research.

Ethics

It is increasingly important for researchers to acknowledge the concept of neurodiversity, which challenges the notion that the person with autism is in some way disordered. Neurodiversity places an emphasis on acceptance and reasonable adjustment – not 'fixing' the individual. This is often criticised for overlooking many of the real challenges faced by individuals and families and creates conflict within the autism movement itself, but must be factored into future research and the development of interventions.

Disagreements regarding the true nature of autism and whether it is a 'disorder or difference' will continue to open the door to questionable approaches. This is why well-designed ethical research is so critical.

Conclusions

Looking forward

As for the future, it is likely that the emergence and growth of computer technology will revolutionise the approach to autism research and treatment by enhancing communication and dissemination of research and by playing to the strengths of the person with autism.

Dissemination of the current state of knowledge is vital and although it is beyond the reach of this chapter to describe all of the different interventions in use, the UK charity Research Autism seeks to publish these findings on its website (www.researchautism.net). A number of research bodies at respected British universities are now working together in the UK.

Theories of autism continue to emerge and fads and fashions come and go. We have come far in our understanding of autism but in other areas, notably research into interventions and the involvement of the autism community itself, progress has been slower. The breathtaking pace of research into human genetics and the neurobiology of autism will undoubtedly redefine our understanding but has important ethical implications. It is important, too, that research is not seen as the domain of academia and that all involved share and develop their work with research institutions so that policy and practice is grounded in empirical evidence.

Looking forward, sustained progress in autism research relies on funding, but also on far-sighted scientists pursuing well-designed programmes, working collaboratively with the autism community.

New technology, the emergence of participatory research and of dedicated research networks such as the International Society for Autism Research (INSAR), is beginning to have real impact and afford new opportunities to improve the quality, relevance and pace of research.

It is impossible to say where this journey will lead but there exists a more positive outlook and greater capacity for discovery than at any time in history. Thanks to the dedicated men and women involved in research, these advances will continue even in an adverse economic environment. As we continue along this path, science will develop in ways that cannot currently be imagined, but humility and compassion must remain at the forefront of our minds.

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Resources

General websites

Ambitious About
www.ambitiousaboutautism.org.uk

Autism Care and Treatment
www.act-today.org

Autism Independent UK
www.autismuk.com

Autism Northern Ireland
www.autismni.org

Autism Research Centre
www.autismresearchcentre.com

Autism Research Institute
www.autism.com/index.asp

Autism Resources Links
www.autism-resources.com/links.html

Autism Society of America
www.autism-society.org/

Autism West Midlands
www.autismwestmidlands.org.uk

Autistica
www.autistica.org.uk

Centre for Autism and Related Disorders
www.centerforautism.com

Center for the Study of Autism
www.autism.org/contents.html

International Society for Autism Research
autism-insar.org

Molecular Autism
www.molecularautism.com

National Autistic Society
www.autism.org.uk

Research Autism
www.researchautism.net/

Scottish Autism
www.scottishautism.org